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ABSTRACT

This final report describes the accomplishments and activities of a project which developed, implemented, and evaluated training activities for medical students, pediatric residents, and practicing physicians to enhance their understanding of and involvement with early intervention and the special education system in Connecticut. The training content developed for medical students is presented in nine self-study manuals grouped under the headings of philosophy, service delivery models, and collaboration. The training content for residents involved presentations, three self-paced training manuals, and practicum experience. Practicing physicians were given presentations and printed materials. Project evaluation focused on the training activities, participant outcomes, and family perceptions of the participants. The project provided training to 30 medical students, 28 pediatric residents, and about 350 practicing physicians. A booklet for physicians was distributed to 500 physicians and a booklet for parents to 400 families. Most of the report consists of appendixes which include: (1) the nine manuals for medical students; (2) the curriculum materials for residents; (3) results of curriculum evaluation by residents; (4) a report on a survey of Connecticut pediatricians concerning early intervention and special education; (5) a summary of the seminars for physicians; and (6) a document on trends in inclusive pediatric services. The main report contains 17 references. Some appendices also contain references. (DB)

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ED 407 770

PHYSICIANS TRAINING PROJECT

FINAL REPORT

U.S. Department of Education
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ABSTRACT

The project developed, implemented, and evaluated training activities for physicians to enhance their understanding of, and involvement with, the early intervention and the special education system in Connecticut. Training was focused on three different audiences of physicians, and early intervention was the primary content area of training. The three training audiences included medical students, pediatric residents, and practicing physicians. The training content included nine subareas grouped under the headings of philosophy, service delivery models, and collaborations with early intervention and special education. The content was developed into self-study manuals and was used with the three audiences of physicians. The first year medical students received training as part of the Introduction to Clinical Medicine Course at the University of Connecticut School of Medicine (UCONN). As part of this course, the students were assigned one patient/family with a chronic illness during the semester. The course required the students to complete home visit hours, meet twice a month to discuss relevant issues, and maintain a written log of their experiences. Pediatric residents (from UCONN) participated in the training project through an expansion of an existing rotation on the Pediatric Care of the Child with Chronic Illness and Disabilities offered through Newington Children's Hospital, a UCONN affiliate. This project enhanced the current rotation through the implementation of training materials, community-based experiences and, most important, home visits with families of children with disabilities. Practicing physicians had a number of options offered to them. Information was disseminated through written materials, Academy of Pediatric meetings, and continuing education activities such as Pediatric Grand Rounds at Connecticut's 33 hospitals and Community Grand Rounds. Evaluation focused on the training activities, participant outcomes, and family perceptions of the participants. Parents were utilized as co-teachers in all of the activities.

Objective 1.0 Manuals Development

Advisory board was convened.

Nine self-study manuals were developed, printed, and field tested with medical students, faculty members, and advisory board members. Revisions were made based on feedback from field testing. The manuals are in a binder titled **Early Intervention and Special Education in Connecticut: The Physician's Role**. The nine manuals include the following topics:

- Family Centered Care
- Education Law
- Research Efficacy
- Role of Other Disciplines
- Curriculum Development
- Natural Instructional Environments
- Service Coordination
- Team Process
- Collaborative Consultation

Each manual contains background information about the topic, a family study/case presentation, discussion questions, discussion answers, and a resolution for the case presentation. Final editions of the manuals were distributed in August 1994 as follows: ICM-A preceptors (20); student preceptors (10); main library reserve shelf (10). A sample manual is in Appendix A.

Objective 2.0 Medical Student Training

Thirty students were matched with families with children with disabilities through other referral sources. A meeting was held for all 30 participating families with children with disabilities and/or chronic health problems. We offered child care and transportation reimbursement for families. The unanimous opinions of the attending families were that they did not want any additional training (other than the informational letter sent by Judy Lewis, course instructor). The students all conduted home visits within the ICM-A course with these families. They also recorded their impression of this experience. This was done through confidential journals kept by the students for their preceptor's feedback. The confidentialty of the patient is maintained during ICM-A as a method to teach "boundaries" to the medical students.

Objective 3.0 Pediatric Resident Training

A residency curriculum was developed, incorporating three of the medical student self-study manuals (Family Centered Care, Education Law, Team Process) and guidelines for the home and program visits. The residency curriculum is titled: **Working Effectively with Families and Their Children with Disabilities**.

Twenty-eight residents participated in the project from July 1993 to December 1994. Starting in March 1994, all residents received training in Family Centered Care, Education Law, and Team Process. Of the 25 residents from March 1994 to March 1996, 25 completed home visits and 11 completed program visits. Completion of program visits was not always possible due to the child receiving services at home only, or due to scheduling constraints on the part of the family, the program, or the resident. None were able to attend IFSP or IEP team meetings. The 4 residents for April and May, 1996 were unable to participate in the project due to the merger of Newington Children's Hospital and Connecticut Children's Medical Center.

Of the families involved, 5 were obtained through the resident's continuity clinic, and the remaining 20 were assigned either through the Children with Special Health Care Needs/Disabled Child Care Clinic or The Family Center. For the program visits, 5 children were in public school settings, 2 were in community day care settings, and 4 were receiving home-based services.

From September 1994 to March 1996, all residents received a binder containing the residency curriculum **Working Effectively with Families**

and their Children with Disabilities. A sample from this curriculum is attached in Appendix B.

Consumer Satisfaction surveys were distributed from September 1994 to March 1996. A total of 16 were distributed, with 10 completed and returned. Results are in Appendix C.

Objective 4.0 Practicing Physician Training

A physician survey was developed and distributed to pediatricians through the Connecticut Chapter of the Academy of Pediatrics. Results were analyzed and became the basis for the content for grand rounds presentations. A copy of the survey results is attached in Appendix D.

Grand rounds presentations were conducted from January 1994 to December 1995. Presenters included staff from Child and Family Studies, the Family Center, and the local Regional Family Service Coordination Center. They were conducted at 14 hospitals in Connecticut, with three hospitals having a second session in the second year. The presentation was also made to the American Academy of Pediatrics Subcommittee on Children with Disabilities and a community-based medical clinic/family practice training program.

The grand rounds presentation agenda was as follows:

- Overview: Introductions, Objectives, The Physicians Training Project

- Federal Law: Key Components of IDEA and Key Components of Part H - Early Intervention

- Shifts in Paradigms: Recommended Practices in Early Intervention and Special Education

- Principles of Family Centered Care

- The Physician's Role in Early Intervention and Special Education

- Procedures for Referral and Service Delivery

- Questions, Need for Information, Other Available Materials, Other Projects

Attendance was taken at 16 of the 19 presentations with the total number of attendees equaling 341.

Another activity under this objective was the development of materials for dissemination at Grand Rounds. A guide called **A Physician's Reference: Services for Children with Disabilities and Their Families** was distributed to over 500 practicing physicians in Connecticut. This booklet describes statewide services, resources, and programs for children with disabilities and their families, what they offer, who is eligible, and how to find them. The booklet was distributed to all grand rounds participants, special interest seminar participants (see below), and to other individuals in the community.

An additional training activity for practicing physicians from the University of Connecticut Health Center, Hartford Hospital, and Newington Children's Hospital, as well as other practicing physicians in the community, and early intervention and school service providers was a group of seminars. This series of four special interest seminars was called: **Current Issues in the Delivery of Services to Children with Developmental Disabilities and Their Families**. The seminars were conducted once a month from September 1994 to December 1994. A summary of the seminars and consumer satisfaction results are attached in Appendix E.

The project also developed an additional training activity and material called: **Family-Physician Alliances for Families of Children with Disabilities**, a booklet titled: **TIPS: Trends for Inclusive Pediatric Services** was given to parents to distribute to their child's pediatrician or primary health care provider. Contents of the TIPS booklet included:

- Introduction and Objectives
- Laws Pertaining to Children with Disabilities
- Family Centered Healthcare
- Cultural Competence

- Care Coordination and The Medical Home
- Communicating with Families
- Collaboration and Alliance Building
- Procedures for Early Intervention Referral
- Community Involvement
- Tools for Enhancing Care
- References and Resources

This booklet was distributed to 400 families and is attached in Appendix F.

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APPENDIX A

Early Intervention and Special Education in Connecticut

The Physician's Role

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All characters in the Family Study section are fictitious. Any resemblance to persons, living or deceased, is unintentional.

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INTRODUCTION

The physician who provides medical care to a child with disabilities plays a key role in the continuing support of the child and his or her family, and recent literature often addresses the role of the pediatrician or family physician in early intervention and special education (Brewer, McPherson & Magrab, 1989; Coury, 1990; Howard, 1982; McInerney, 1984; Shonkoff, Dworkin & Leviton, 1979). Federal law acknowledges the importance of the physician and health services by including them as components within the statewide system of early intervention. In reality, however, in few states are the health system, and the pediatrician or family practitioner, well integrated into the statewide system. As a child ages into the special education system (age 3-21), the gap between the child's medical care and his or her educational services only increases (Eaton, Coury & Kern, 1989). One reason for this may be physicians' lack of awareness of and knowledge about their role in state systems of early intervention and special education. This is not surprising, considering that neither the preservice nor the inservice training of pediatricians places much emphasis on the care and management of a child with disabilities. However, the emphasis of Part H of the Individuals with Disabilities Education Act (IDEA) on the importance of a multidisciplinary team for early intervention has stimulated interest in improving pediatricians' training (for example, Coury, 1990; Peter, 1992; Schwab, 1991).

The American Academy of Pediatrics (AAP) has been active in developing comprehensive medical education programs to meet the needs of pediatricians in practice. In 1978 an AAP specialty task force released a report which assessed the health needs of children and the educational needs of the pediatricians who treat them. Among the conclusions of the task force were that 1) all pediatricians should have the skills to cope with biosocial and developmental problems; and 2) residency programs need to emphasize training in the provision of care to children with chronic handicapping conditions (The Task Force on Pediatric Education, 1978). That same year, the Office of Special Education and Rehabilitation Services of the US Department of Education gave the AAP funding to develop an inservice training curriculum that was used with over 5,000 primary care physicians who serve children with disabilities (Powers & Healey, 1982). Since then, however, few programs have had such scope and ambition (Coury, 1990).

Researchers have advocated for many years (Dworkin, Shonkoff, Leviton, 1979; Haggerty, 1974) that pediatricians receive continuing education on the care of children with disabilities. Recent recommendations have focused on educating pediatricians to provide a medical "home" for the primary medical care of each child (Koop, 1987). This home should be comprehensive, coordinated, family-centered, and community-based. The concept of such a home has been endorsed by the AAP and by the Bureau of Maternal and Child Health (National Center for Networking Community-Based Services, 1989). In order for physicians to provide services based on this model of medical care, however, they first must receive training.

A 1993 survey of practicing Connecticut pediatric/family physicians showed not only a need for additional medical school/residency training on children with disabilities, but also on the early intervention and special education systems from which these children receive services. This survey was conducted by the University of Connecticut Health Center's Division of Child and Family Studies Physicians Training Project.

Training Manuals

This training manual is a response to the Connecticut physicians' request for medical school students to receive additional training on children with disabilities. This manual will provide information to practicing pediatricians, pediatric residents, and medical students regarding their involvement with the early intervention and special education systems, in their capacity as primary physicians for children with disabilities and their families.

The three areas of training will include: 1) philosophy, 2) service delivery models, and 3) collaborative relationships. Figure 1 contains an overview of the content and organization of the training manuals. In the center of the figure stands the family; this reflects the project's central philosophy and its commitment to family-centered care.

All training materials and activities are founded on the beliefs that:

- The physician must see the family as the constant in the child's life, and the primary unit for the delivery of services.

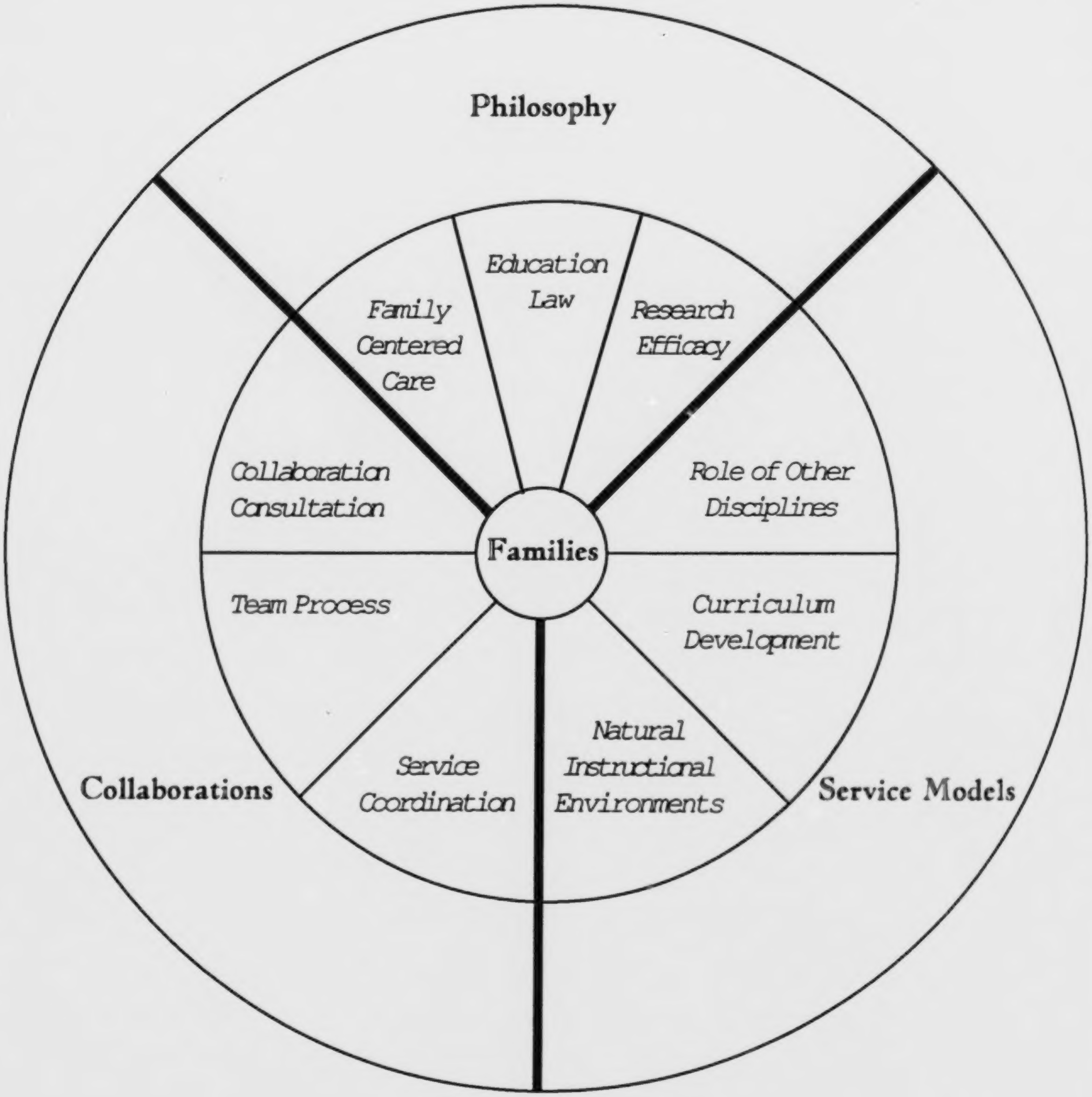
Philosophy
Education Law
Family Centered Care
Research Efficacy
Collaboration Consultation
Role of Other Disciplines
Families
Team Process
Curriculum Development
Natural Instructional Environments
Service Coordination
Collaborations
Service Models

Figure 1. Overview of Material Content and Organization.

- Family-centered, community-based care must be available for all children, regardless of disabilities, illnesses, and cultural backgrounds.
- Intervention models must be designed to accommodate families of various cultures and backgrounds.
- Innovations in family-centered services must be translated into standard community practice.
- Collaboration needs to be ongoing among service providers and between service providers and families.
- A primary goal is the inclusion of children with disabilities in all normal activities and situations wherever and whenever possible.

This training guide consists of eight self-study manuals. Together, they are designed to enhance physicians' understanding of their role in the early intervention and special education systems by exploring related topics. Each manual is similar in layout and has been designed to provide physicians with an opportunity to apply the information they have learned. The manuals are divided into four components. The **first component** discusses concept and values: What is the concept? Why is it important? How does it relate to children with special needs? The **second component**, the family study, gives the general background, both medical and family histories and the challenges this family is facing. The **third component**, the discussion, provides physicians with an opportunity to apply the concepts learned to the family situation described. The **last component**, the resolution, provides a hypothetical resolve which emphasizes physicians defining their roles and responsibilities.

The manuals should be studied in the following order:

1. Family Centered Care
2. Education Law
3. Research Efficacy
4. Role of Other Disciplines
5. Curriculum Development
6. Natural Instructional Environments
7. Service Coordination
8. Team Process
9. Collaborative Consultation

These self-study manuals are part of the training that will be individually designed for each audience: the major thrust of this training is to enable medical students, pediatric residents, and practicing physicians to participate within the early intervention or special education system for children with disabilities and/or chronic illness.

References

Brewer, E., McPherson, M., Magrab, P., & Hutchins, V. (1989). Family-centered, community-based, coordinated care for children with special health care needs. Pediatrics, 83(6), 1055-1060.

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The Task Force on Pediatric Education. (1987). The Future of Pediatric Education. Evanston, IL: American Academy of Pediatrics.

I. Introduction and Overview

This project developed, implemented, and evaluated training activities for physicians to enhance their understanding of, and involvement with, the early intervention and the special education system in Connecticut. To maximize impact, the training was focused on three different audiences of physicians. The three training audiences included medical students, pediatric residents, and practicing physicians. The training content included nine sub-areas grouped under the headings of philosophy, service delivery models, and collaborations with early intervention and special education. The content has been developed into self-study manuals which were used with the three audiences of physicians. The first year **medical students** received training as part of the current Introduction to Clinical Medicine Course at the University of Connecticut School of Medicine (UConn) over three years. As part of this course, the students were assigned one patient/family with a chronic illness during the semester. The course required the students to complete nine home visit hours, meet twice a month to discuss relevant issues, and maintain a written log of their experiences. This project enhanced this course through the addition of formal materials and activities on the early intervention and special education system, and the addition of field experiences within early intervention and special education programs. Twenty-eight **pediatric residents** (from UCONN) participated in the training project through an expansion of an existing one month rotation on the Pediatric Care of the Child with Chronic Illness and Disabilities offered through Newington Children's Hospital, a UCONN affiliate. This experience was hospital-based. This project enhanced this rotation through the implementation of training materials, community-based experiences, sessions with staff and families at the Family Center and, most importantly, home visits with families of children with disabilities. **Practicing physicians** had a number of options offered to them. Information was disseminated through written materials, Academy of Pediatric meetings, and continuing education activities, such as Pediatric Grand Rounds at Connecticut's 33 hospitals. An additional series of seminars were offered to them. This component included family medicine physicians, as well as pediatricians. Over 750 physicians participated in training and 2,000 received training materials. It should be noted that there are no continuing education requirements by the state for practicing physicians in Connecticut. Evaluation focused on the training activities, participant outcomes, and family perceptions of the participants. Parents were co-teachers in all of the activities. The project was a collaboration between the University of Connecticut Department of Pediatrics, and Newington Children's Hospital Center for Children with Special Health Care Needs and the Family Center at Newington.

Background

The role of the pediatrician or family physician in early intervention and special education has been addressed in the literature (Bredekamp, 1993; Coury, 1990; Howard, 1982; McInerny, 1984; Shonkoff, Dworkin, & Leviton, 1979). The physician who provides medical care to a child with disabilities plays a key role in the ongoing support of the child and his/her family. Federal law acknowledged the importance of the physician and health services by including them as components within the statewide system of early intervention. In reality, however, there are few states where the health system, and the pediatrician or family practice provider, are well integrated into the statewide system. As a child ages into the special education system (age 3-21) the gap between the child's medical care and educational services only increases (Eaton, Coury, & Kern, 1989). **It has been suggested that one reason for this situation is a lack of awareness and knowledge on the part of the physicians about their role in state systems of early intervention and special education.** This is not surprising considering that there is very little emphasis placed on the care and management of a child with disabilities throughout both the preservice and inservice training of pediatricians. However, the emphasis placed on the importance of a multidisciplinary team for early intervention by Part H of IDEA has stimulated interest on improving this situation (e.g., Coury, 1990; Melmed, 1991; Peter, 1992; Schwab, 1991).

The American Academy of Pediatrics (AAP) has been active in the development of comprehensive medical education programs to meet the needs of pediatricians in practice. In 1978 a specialty task force released a report on pediatric education. This task force assessed the health needs of children and the educational needs of the pediatricians who assess the children. Among the conclusions of the task force were that 1) all pediatricians should have the skills to cope with biosocial and developmental problems; and 2) residency programs need to emphasize training in the provision of care to children with chronic handicapping conditions (The Task Force on Pediatric Education, 1978). That same year the Office of Special Education and Rehabilitation Services of the US Department of Education funded the AAP to develop an inservice training curriculum that was used with over 5,000 primary care physicians who serve children with disabilities (Powers & Healy, 1982). Since then, however, there have been few programs which have had the scope and effort of this program (Coury, 1990).

The AAP has continued to develop other training materials for use with physicians and others involved with services for children with disabilities. For example, Project BRIDGE was developed for interdisciplinary teams providing early intervention services to children aged birth to three and their families (Spencer & Coye, 1988). This program provides training to physicians in the context of a broader interdisciplinary focus. Unfortunately, most of the AAP's current efforts on continuing education for children with disabilities have focused on training workshops at the academy's annual meeting (Dworkin, personal communication, June 3, 1992).

In an effort to expand a physician's knowledge base on children with disabilities from a preservice perspective, a number of initiatives have been implemented by medical schools around the country. For example, there are a number of fellowship programs in developmental pediatrics. These programs focus-on such areas as: knowledge about a variety of relevant issues such as disabilities; health legislation and policy planning; psychological aspects of chronic conditions; and the interdisciplinary process. Unfortunately the number of fellows graduating from such programs is small, though, funding provided by the Bureau of Maternal and Child Health, US Department of Health and Human Services, supports a dozen centers now offering this type of advanced program.

Recent years have seen an increasing number of medical schools that are implementing curriculum on children with disabilities at the residency training level. Most programs, such as those at Ohio State, the University of Minnesota, and the University of Connecticut, provide a one month rotation for residents focused on children with disabilities and chronic illness. Some type of structured curriculum is usually used by these programs (e.g., Guralnick, Richardson, & Heiser, 1982). Other programs, such as those at Michigan State University, the University of Vermont and the University of Maryland are expanding these experiences to include a long term relationship with a family with a child with disabilities during the entire residency period. Again, these programs are relatively unique. However, there has been encouragement to expand these experiences for pediatric residents as we move toward full implementation of Part H of IDEA (Brewer, McPherson, Magrab, & Hutchins, 1989).

Continuing education programs for pediatricians on the care of a child with a disability have been advocated for many years (Dworkin, Shonkoff, Leviton, & al., 1979; Haggerty, 1974). Recent recommendations have centered around providing education to pediatricians to enable them to provide a medical "home" for the primary medical care of each child (Koop, 1987). This home should be comprehensive, coordinated, family-centered, and community-based This concept has been endorsed by the AAP and the Bureau of Maternal and Child Health (National Center for Networking Community-Based Services, 1989). In order to provide the training necessary to ensure the implementation of this model of medical care, training activities must be available. In Hawaii, for example, the state Health Department has been providing a variety of activities for pediatricians (Peter, 1992). These activities are supported by both the agency for Part H services and the state chapter of the AAP.

There are a number of barriers to expanding the scope of medical education, residency training, and continuing education for pediatricians. Among these are the cost of the additional training time and the over crowded nature of the currently existing curricula offered to medical students and residents. This project attempted to overcome these barriers through the development and implementation of the following training objectives and activities:

FAMILY CENTERED CARE

The family is the constant in every child's life.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe the Family Centered Care philosophy.**
- **Apply the nine principles of Family Centered Care.**

Philosophy

Family Centered Care is a philosophy developed by the former Surgeon General, C. Everett Koop, M.D., Sc.D. **It is a philosophy of care which encompasses family centered, community based, coordinated services for children with special health care needs and their families.** A major premise of this approach is that the child is part of a family, and the family has, of course, great impact on the development and well being of the child. A family centered approach to providing services to the child and his or her family thus depends on building and maintaining a relationship based on mutual trust and respect between professionals and the family

The principles of Family Centered Care were further defined and expanded upon in Family Centered Care for Children with Special Health Care Needs, published by the Association for the Care of Children's Health (ACCH) in 1987. In 1990, with input from a large group of families and providers of services to children with complex health care needs, ACCH revised and expanded the original number of principles to the nine which are currently accepted. These nine principles are to develop systems of care that would: 1) assist in the delivery of services to children with special health care needs and 2) support the needs of the family (Shelton, Jeppson, and Johnson, 1987).

In a family centered approach to serving children with health care needs and disabilities, doctors and other professionals no longer play their traditional roles. Thus all health care professionals should review the family centered priciples discussed here to ensure that the services they provide meet the needs of both the child with special needs and the family who is the center of care for that child.

The Nine Principles of Family Centered Care

1. **Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.**

   As a child grows and moves through the service delivery system, he or she will be involved with many professionals, specialists and agencies--but the family will always be there, the single and most important source of constant support for their child. It is essential that professionals recognize and respect this central role that the family plays in the care of their child. Ultimately, each family must assume responsibility for their child's care, both daily and for the long term. Professionals must learn to work in partnership with each family, valuing their judgment and respecting their values and vision.

2. **Facilitation of parent/professional collaboration at all levels of health care.**

   Successful care plans must be developed through a meaningful collaboration that reflects each family's strengths and is tailored to each family's needs. The ultimate success of this process depends on the ability of parents and professionals to work in partnership. In a family centered model the family is in charge and the professionals serve as consultants in the child's care.

3. **Sharing of unbiased, complete information with the parents about the child's care on an on-going basis and in an appropriate, supportive manner.**

   A true partnership between parents and professionals requires that parents have access to complete information, written in an understandable way, and in the family's primary language. This information includes: diagnosis and prognosis; available resources, including funding for services; and current research data.

4. **Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of the family.**

   Because each family is unique, the support that each requires reflect their individual values, strengths, coping styles, and visions for the future. Family support therefore means "whatever it takes" for the family to achieve its goals and visions: this philosophy assumes that the family is in the best position to determine exactly what they will need. The needs may include funding, respite, child care, service coordination, parent-to-parent support, transportation, adaptive equipment, housing modifications, and advocacy.

5. **Recognition of family strengths and individuality with respect for different methods of coping.**

   Each family has its own strengths and sources of support: these may include neighbors, extended family, friends, and community associations. Professionals should work with the family to identify these support networks and develop strategies to strengthen and reinforce them. In addition, each family is defined differently and may include friends, as well as grandparents, brothers, sisters, aunts, and uncles. Services must be tailored to fit around this unique family system with its own specific goals, values, culture, and coping style.

6. **Understanding and incorporating the developmental needs of infants, children, and adolescents, and their families into health care systems.**

   In addition to each child's health care needs, a comprehensive health care plan must address other issues as well. Because each child and family has need for socialization, development, and community support, the care plan should allow each parent to fulfill his or her role as parent, and each child to have as normal a life with family and friends as possible.

7. **Encouragement and facilitation of parent-to-parent support.**

   Support from other families is valuable in developing successful coping strategies. Parent-to-parent support may involve matching experienced or "veteran" parents with a parent newly referred into the service delivery system. The veteran parents receive training in their roles as parent-to-parent support group volunteers, and each parent-to-parent support group is coordinated by a parent. Family supports can also include parent groups, led by professionals.

8. **Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs.**

   The needs of each child and family will change over time. It is critical, therefore, that service providers be able to respond to these ever-changing needs through a flexible, accessible, and responsive system of services. Families often report that inflexible service systems and friction between parents and professionals are greater sources of stress than the daily care of their child with complex care needs. They report stresses such as rigid and conflicting eligibility criteria, confusing application forms, turf battles among agencies and service providers, and a fragmented, difficult-to-access system of services.

9. **Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.**

   Each family has its own beliefs, values, strengths, and needs, and professionals need to guard against imposing their own values or cultural expectations upon the family. Care plans must enhance the family's strengths and address only those needs which the family itself has identified, rather than those which professionals believe exit.

Table 1 provides questions physicians should ask themselves to help ensure they are providing family centered care:

Table 1

Topic	Questions
Family is Constant	• Have I identified the **family's** needs? • What can I do to help meet their needs? • Have I solicited the family's input? • Have I taken the family's needs into account when making my decisions?
Collaboration	• Have I met with or contacted all the professionals serving this family? • Have I let the family and professionals know how to contact me?
Information	• Have I been completely honest with the family regarding their child's condition? • Have I been supportive to the family, helping them to adjust to the needs of their child? • Have I presented all information in a clear and understandable way (particularly, in the family's primary language)?
Policies and Programs	• Have I informed the family of an agency that can help them deal with all issues related to the care of their child (for example, funding, education, service coordination, parent-to-parent support, transportation, adaptive equipment, housing modifications, and advocacy)?
Strengths and Individuality	• Have I helped the family identify its strengths? • Am I aware of the individual needs of this family?
Developmental Needs	• Does the treatment I prescribed allow the family and child to meet their normal needs?
Support	• Have I encouraged the family to seek out the support of other families and agencies?
Healthcare	• Have I clearly let the family know of the services they qualify for? • Have I collaborated with other professionals involved with this family to make sure the family is aware of all possible services that they qualify for? • Have I responded to the family's needs?
Families	• Have I considered the family's culture and values when prescribing my treatment?

FAMILY STUDY

JP is about to be discharged from the newborn intensive care nursery after a twenty-week hospitalization following his premature birth. He developed seizures at 72 hours, which were controlled by medication, and required ventilation for three weeks. He also had difficulty feeding by mouth. His mother, Susan, is a seventeen-year-old single parent in good health. She works an average of 30 - 40 hours a week, with no insurance benefits, as a secretary for a temporary employment agency. Susan must continue to work after JP comes home, and would like to find a permanent position with benefits. She worries about how she will pay for all of JP's needs.

Susan lives alone, and JP's father is not involved with the family. She has no family living nearby to assist her with JP's care; however, Susan does have a few close friends who have visited JP with her at the hospital. Susan will need support in her roles as primary provider of JP's care and as primary decisionmaker for his health care needs.

Susan had some difficulty keeping her schedule of hospital visits, although when she did visit JP she often sat and rocked him for hours. Her missed visits made it difficult for the hospital staff to adequately train Susan in JP's care; however, toward the end of JP's hospitalization, Susan arranged for two days and one overnight at the hospital so she could learn JP's care plan and participate in the discharge-planning process.

Susan lives in a one-bedroom apartment across town from the hospital. She does not have a telephone, so that maintaining contact with the hospital when she could not visit was difficult.

JP has a number of continuing medical concerns, including a need for seizure medication, and assistance during feedings. Because his muscle tone is poor, he is unable to suck for long periods. His calorie intake must therefore be monitored to make sure he gains enough weight.

Susan is committed to having him with her, but has a number of questions she would like answered before she takes JP home. The hospital social worker questions Susan's abilities to adequately care for JP. As the community pediatrician who will be caring for JP, you are responsible for making sure the transition to home goes smoothly.

DISCUSSION

As JP's primary pediatrician, apply the nine principles of Family Centered Care to identify the following:

What are the family's strengths and resources?

What are the family's needs/concerns?

Who should explore the issues affecting Susan's ability to visit JP in the hospital and to participate in his care? How should these issues be addressed? What is the family's role in discharge planning?

What are the potential barriers to implementing the discharge plan?

Who addresses the barriers identified in the discharge meeting?

What are the providers' (professionals) issues?

What do you want included in the discharge plan for JP?

RESOLVE

Using a family centered model, the following people began discharge planning for JP and Susan after the sixth week of JP's hospitalization, when his health stabilized:

Susan
Primary NICU Physician
Primary Nurse
Discharge Planner (Nursing)
Social Worker (Hospital Based)
Visiting Nurse (Community Based)
Community Physician

The discharge planning included three full team meetings: at 8 weeks, 16 weeks, and just prior to discharge. Susan was able to attend only one of these meetings, but met with JP's primary nurse before and after each meeting to discuss the plans. Susan also met with the social worker on four other occasions, during visits to the hospital. The visiting nurse made one visit to Susan's home before discharge and made an assessment of JP's home care needs.

In these meetings the team explored the strengths and needs of the family. Susan was strongly determined to care for JP at home, and managed to get time off from work to visit JP and participate in the discharge planning. During the two days and one night she spent at the hospital prior to discharge, she learned how to care for JP, including how to operate all his medical equipment. Despite limitations in transportation, she did manage to visit JP. She is very nurturing towards him, spending hours in the hospital just rocking and hugging her baby. She has a few friends who provide her with some emotional support. Susan has managed to keep her job despite the stress and trauma of JP's hospitalization, and is struggling to meet both of their needs.

During the discharge planning process, Susan identified several concerns, including a lack of insurance benefits, and concern over how JP's hospitalization and continuing care needs will be paid for. She will need to find child care for JP, and expects that this will be difficult because of his medical and developmental needs. She also has neither a car of her own nor access to one, for getting to appointments; furthermore, she is concerned about taking too much time off from work. She is also worried about the possibility that JP will have long-term care needs and will be disabled. She has no one to support her and assist her in understanding these issues.

The team wrote the discharge plan at their last meeting, and team members carefully explained the plan to Susan. A referral for early intervention was discussed with Susan and she said she would think about it. Her copy of this document included, in addition to telephone numbers and appointments, the following:

- What medical equipment to obtain from a home-health supply vendor
- Proper dosage and administration of medication for seizures
- Referral to early intervention services for developmental follow-up and physical therapy

- Referrals for follow-up in the following specialties: ophthalmology, neurology, pulmonology, audiology, and developmental follow-up clinic
- Referral for eight hours of home nursing per day

In addition to JP's medical/developmental needs, Susan's other concerns were addressed through the discharge plan.

Susan's need for a telephone. The hospital social worker secured a donation from a local charitable foundation to have a phone installed; Susan understands that ongoing bills will be her responsibility.

Health care financing. Susan was assisted in applying for Medicaid (Title XIX) and WIC (Food supplement for pregnant women, infants and children). At the time of JP's discharge, she had met the eligibility requirements: JP's care, as well as her own, was covered.

Transportation. Medicaid will pay for transportation to medical appointments.

Multiple care providers and appointments. The visiting nurse agreed to act as a service coordinator, and will assist Susan in coordinating appointments on the same day.

Support needs for Susan. Prior to JP's discharge, Susan was offered support through Parent-to-Parent, a network of trained "veteran" parents who have children with disabilities. She was matched up with another mother, who visited her several times at the hospital, and they planned to continue meeting after discharge. The discharge plan also contained a referral to an employment counseling agency which will help Susan find permanent work.

Child care needs for JP. JP will receive eight hours a day of home nursing while Susan is working; this coverage will continue as long as JP needs skilled care. Should his condition improve, Susan will again need to find child care. The Visiting Nurse Association will assist her in training someone, but Susan is aware that this care may be costly and difficult to secure.

With the appropriate support, including a good relationship with JP's primary care pediatrician, Susan and JP can have a satisfying life together.

DISCUSSION - ANSWERS

As JP's primary pediatrician, apply the nine principles of Family Centered Care to identify the following:

What are the family's strengths and resources?

- Susan loves JP
- Susan's strong determination to provide care for JP at home
- Susan took time off from work to participate in the planning process for JP's discharge
- Susan visited JP despite transportation difficulty
- Susan has some friends for emotional support
- Susan has kept her job throughout the stress and trauma of JP's hospitalization

What are the family's needs/concerns?

- Insurance Benefits
- Child care
- Transportation
- Help coordinating JP's doctors' appointments
- Support for Susan to help her understand JP's needs
- Employment counseling for Susan

Who should explore the issues affecting Susan's ability to visit JP in the hospital and to participate in his care? How should these issues be addressed? What is the family's role in discharge planning?

- Susan, JP's pediatrician, primary care nurse, and social worker (discharge planning team) should be involved in identifying the issues affecting Susan's ability to visit JP in the hospital and participate in his care
- These issues should be addressed in a team meeting of the above individuals in a collaborative, family centered manner; they should all work toward the goal of JP being cared for at home with his mother
- The family's role should be as an equal team member in the discharge planning

What are the potential barriers to implementing the discharge plan?

- Susan's need for a telephone
- Health care financing
- Transportation
- Susan's ability to get JP to multiple appointments without losing her job
- Susan's support needs
- Child care

Who addresses the barriers identified in the discharge meeting?

- The entire discharge-planning team should address these issues

What are the providers' (professionals) issues?

- Making sure JP has his medical needs met at home, including medical equipment, medicine, therapy and appropriate medical and early intervention referrals

What do you want included in the discharge plan for JP?

- Medical equipment from a home health supply vendor
- Medication for seizures
- Referral to early intervention and physical therapy
- Referrals for medical follow-up appointments

REFERENCES

Koop, C.E. (1987). Surgeon General's Report: Children with Special Health Care Needs - Campaign '87 - Commitment to Family-Centered, Coordinated Care for Children with Special Health Care Needs. Washington, DC: US Department of Health and Human Services.

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Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Family Centered Care Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

EDUCATION LAW

The Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) address many facets of the child's educational and health care needs.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe the Individuals with Disabilities Education Act (IDEA) and apply concepts of the law to children with disabilities.**
- **Describe Part H of IDEA (early intervention) and list the services available for eligible infants and toddlers.**
- **Describe the Americans with Disabilities Act (ADA) and apply concepts of the law to children with disabilities.**

As the primary physician treating children with disabilities, it is important for you to become familiar with the laws affecting the education of these children. These laws have many components and specific provisions; we describe below two of the most important laws affecting children with disabilities, and the key provisions of those laws.

Individuals With Disabilities Education Act

The Beginning: The Education for All Handicapped Children Act

In 1975, The Education for All Handicapped Children Act (P.L. 94-142) became law; it guaranteed children with disabilities the right to a free and appropriate public education. This legislation was the culmination of many years of court decisions and legislation expanding access to education for children with disabilities. The Education for All Handicapped Children Act mandated a free and appropriate public education for children with disabilities **ages 5-21** regardless of the nature or severity of the handicap.

The Education for All Handicapped Children Act defines **special education** as "specially designed instruction, delivered at no cost to the parent, to address the unique needs of the child" in accordance with an **Individualized Education Plan (IEP).** The child may receive this instruction in the classroom, in the home, in hospitals and institutions, and in other settings, such as community early childhood programs.

The Amendments

In 1986, Congress amended P.L. 94-142 to P.L. 99-457, and added a number of specific components significant for **children under age five**. **Part B** of this amendment stipulates that:

- services for children who are age 3-5 and who are determined to be eligible for special education are **mandated** under the provisions of a free and appropriate public education
- services are to be provided to each eligible child or adolescent regardless of the severity of the individual's disability

Part H, Early Intervention Services For Infants And Toddlers created incentives for states to develop an early intervention entitlement program for children **from birth through age three**. This part of the law describes a comprehensive statewide system of interagency, multidisciplinary services that should be available to eligible children. Each state must determine its own eligibility criteria. Many states, such as Connecticut, now provide very young children with such early intervention services, under a state mandate which complies with the federal Part H requirements. Many important services specified by Part H are available to families of eligible infants and toddlers:

- Each eligible infant or toddler and his or her family shall receive a multidisciplinary assessment and an **Individualized Family Service Plan (IFSP)** which should include:
    - a) the present level of the child's development
    - b) a statement of the family's priorities, resources, and concerns
    - c) a statement of expected major outcomes for the child
    - d) a statement of necessary services for the child
    - e) projected dates of these services, and their duration

f) the steps for supporting the child's transition to the mandated school program

g) the name of a service coordinator

- Each state is required to establish a **State Interagency Coordinating Council** whose role is to advise and assist the lead agency for early intervention. The membership of the state **ICC** will include at least:

    a) three parents of infants or toddlers with disabilities

    b) one representative from the state legislature

    c) three public or private providers of early intervention services

    d) one person involved in professional preparation

    e) other representatives from each of the appropriate agencies involved in the provision of or payment for early intervention services

    f) others appointed by the Governor

In 1991, these amendments to P.L. 94-142 were passed; the law became P.L. 101-476 and was renamed the **Individuals with Disabilities Education Act (IDEA).** The name change reflects a shift in terminology from "handicaps" to "disabilities".

Under **Part A General Provisions**, this law stipulates that:

- A free, appropriate public education is assured for all eligible children with disabilities
- The eligible disabilities include mental retardation, hearing impairments, speech and language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, and specific learning disabilities

- **Related services** (see Appendix A) be provided, including:

  transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education: these include speech pathology and audiology, psychological services, physical and occupational therapy, recreation (including therapeutic recreation), early identification and assessment of disabilities in children, counseling services (including rehabilitative counseling), and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling and training.

- Transition services for secondary-age students

The Major Components of IDEA are:

The Zero Reject Principle: A free, appropriate public education is guaranteed for all children ages 3-21 regardless of the severity of the individual's disability. Children under three may be provided with services if state law, regulation, or judicial ruling mandate them.

Nondiscriminatory Assessment: A multidisciplinary team must conduct the evaluation in the child's primary language or mode of communication, using observations and non-biased, validated instruments. The student must be assessed in all areas related to the suspected disability. The assessment should allow the child to display his or her abilities and strengths, as well as disabilities.

Individualized Education Plan (IEP): An appropriate Individualized Education Plan must be written for each child. This document should be developed in a Planning and Placement Team (PPT) meeting composed of parents, a school administration representative, the child's teacher, members of the evaluation team, and others invited by the parents or the school. The IEP will contain a statement of the child's current level of performance, long term goals and short term objectives, specific educational services the child will need, the date for beginning services and the anticipated duration of the services, the extent of the child's participation in the regular education program, and how to determine whether the goals and objectives for the child are being met.

Least Restrictive Environment (LRE): To the maximum extent possible, schools must educate children who have disabilities with their peers who do not have disabilities:

- Special classes, separate schooling, or otherwise removing a student with disabilities from regular education should occur only when the nature or severity of the disability is such that education in regular classes cannot be achieved satisfactorily even with the use of supplementary aids and services.
- Schools must provide a spectrum of placement options (regular classes, regular classes with minimal support, regular classes with one-to-one assistance, and so on) and supplementary services (adaptive physical education, speech and language, and so on.)
- Schools must provide education as close to the student's home as possible, and allow a student to participate in extracurricular and nonacademic activities to the extent appropriate.
- If a child with disabilities, is removed from a regular education classroom, the school must work to return that child to the regular classroom as soon as possible.

Due Process and Parent Participation: School districts must establish and follow specific procedures in order to protect the rights of children and their families. These procedures should specify that:

- Parents may examine all records pertaining to their child.
- Parents have the right to obtain an independent evaluation of their child, in addition to that provided by the school district and its staff.
- Parents must be given the opportunity to consent or object to the identification, evaluation, or placement of their child. They must be informed of the Planning and Placement Team (PPT) conference and encouraged

to participate. Meetings must be scheduled at times convenient for parents and appropriate communications must be maintained with them.

- Parents or guardians must receive written notice if a change is proposed in their child's classification, evaluation, or educational placement.

- Parents have a right to an impartial due-process hearing conducted by a hearing officer, and/or mediation if they are in disagreement with the school district. Parents have the right to be represented by a lawyer, to give evidence, and to cross-examine. Hearings may be requested by the parent or by the school district.

- Surrogate parents must be appointed to provide representation and informed consent for children whose parents or guardians are not known, or who are not available.

In addition to the above provisions these amendments include an emphasis on meeting the needs of traditionally under-represented populations (for example, minorities or low-income families). The amendments also expand the definition of special education to include a variety of settings for the delivery of services (for example, a work place or community-based program). States must also insure that **assistive technology devices** and/or **assistive technology services** are made available to a child with a disability if they are required as a part of the child's program. Thus, a child's program may include special education, related services, and/or supplementary aids and services. The legislation states, further, that the related-services list is not exhaustive and may include other developmental, corrective or supportive services, if they are required to assist a child with a disability to benefit from education.

Americans With Disabilities Act (ADA)

The Americans with Disabilities Act (ADA) signed into law by President George Bush on July 26, 1990, is a wide-ranging civil rights law that prohibits discrimination against people with disabilities. The protections it offers are similar to those given to women, minorities, and others subsequent to the Civil Rights Act of 1964. ADA protects an estimated 43 million Americans with physical or mental impairments that substantially limit their activities, such as working, walking, talking, seeing, hearing, or caring for themselves. People who have such impairments, as well as those who are perceived to have impairments, are also protected.

ADA bars discrimination in employment and requires most employers to make **reasonable accommodations** for employees with disabilities. It also prohibits discrimination in commercial facilities, with regard to public accessibility, as well as discrimination in any activity or service operated or funded by state or local government. This may include daycare centers and others programs which serve children without disabilities.

FAMILY STUDY

Trevor is a nine year old boy who lives with his mother, Sandy, and his father, John. Trevor has two sisters; Lisa, who is six years old, and Ann, who is four. Sandy delivered Trevor 12 weeks prematurely by emergency Cesarean Section. Trevor's birth weight was low, and he was hospitalized for four months because of repeated respiratory distress. Sandy and John visited their son regularly in the hospital and were involved in his hospital care.

Trevor was discharged from the hospital with respiratory problems and required frequent feedings and medications. His parents cared for him at home with little support. Trevor has developmental delays, as documented by a multidisciplinary evaluation requested by his parents shortly after he came home from the hospital at six months of age. Trevor began receiving early intervention services at fifteen months of age. This is Trevor's condition:

- Trevor has cerebral palsy; he is, however, ambulatory.
- He has a marginal airway.
- He currently wears prescriptive lenses and requires preferential seating in school.
- Trevor has repeated bouts of respiratory infections for which he often receives antibiotics.
- Trevor has learning disabilities.
- He has attention problems which require medication.

Presently, Trevor is in a "self-contained" classroom (for students with learning disabilities) at a grade level (4) appropriate for his age. This is the first year that Trevor has been in the self-contained classroom. The school staff believed that this was the most appropriate place for him to be for several reasons, which they clearly communicated to Trevor's family. The reasons for his placement included:

1. Trevor often required that instructions about assignments be repeated.
2. Trevor's behavior in the mainstream or "regular ed" (for non-disabled peers) classroom was often disruptive, and the teacher had a difficult time getting him and the rest of the class back on task.
3. Class sizes were increasing, and the teacher would not be able to give Trevor the more "personalized" instruction he might need.
4. The school staff judged that Trevor's learning disability and his physical disability dictated a more "restrictive" educational setting.

His parents initially agreed to place Trevor in a self-contained program, and this was implemented in his IEP. His mother now feels that this program is not in Trevor's best interest, and has requested that Trevor be placed in a regular-education classroom with individualized support services. She is upset that Trevor has to attend a different school than the other children in the neighborhood, since the self-contained program for his grade level is offered in only one school in the city. Also, he is not attending the same school as his sister Lisa, which makes childcare arrangements even more difficult to manage.

Trevor's parents requested a Planning and Placement Team (PPT) meeting because they were displeased with the school's response to their concerns. At his parent's request, Trevor's neurologist wrote a letter supporting Trevor's placement in a "regular ed" setting with modifications. His mother believes that Trevor's behavior has worsened since he has been in the self-contained class, and Trevor's pediatrician is concerned that he may be acting out his anger about being unhappy at school.

To act as an advocate at the PPT, Trevor's parents brought along a distant cousin of Sandy's, a special education teacher who had been involved in discussions about Trevor's placement in the past. The PPT lasted three hours, but the participants could not reach an agreement. Trevor's parents then filed the appropriate forms with the Department of Education to begin due process to resolve this dispute. They see his educational needs as:

- Modifications to the curriculum and/or classroom day in order to assist him in learning
- Trevor being allowed to have appropriate interaction with his peers, in order to establish positive relationships
- An appropriate evaluation to assess Trevor's current educational needs

DISCUSSION

As Trevor's primary physician, evaluate the following:

According to the Individuals With Disabilities Education Act (IDEA) and Americans With Disabilities Act (ADA), what should be your role in addressing Trevor's educational needs?

Based on the information presented regarding Trevor's educational needs, does the Individuals with Disabilities Education Act afford Trevor the opportunity to participate in a regular education program?

If, according to the IDEA, Trevor should participate in a regular education program, what part or parts of the IDEA specifically address Trevor's educational needs?

What are the parental and family issues? How has the family appropriately asserted their right to have those issues taken into consideration when Trevor's IEP is developed?

If Trevor were two years old, how might this process be different under IDEA Part H?

RESOLVE

Sandy and John filed for a due process hearing for their son, Trevor, with the local school district. As the law states, the State Department of Education must schedule the hearing and render a decision within 45 days of the initial request for the hearing. Sandy and John thought that up to this point they had a working relationship with Trevor's school team; after discussing the issue, they decided to ask the school district officials if they would instead be interested in mediation. The law (P. L. 101-476) does allow for mediation, which is defined as an informal process for resolving disagreements about a student's special education evaluation, program, or placement. In order to obtain mediation, both the parent or guardian and the school district must send written requests to the State Board of Education. The School District agreed to try mediation; the State Board of Education then scheduled a mediation date and appointed a state mediator to help work out a solution acceptable to both parties. The family understood that if mediation did not work, their initial request for a due process hearing would still be valid.

Trevor's parents decided to ask his neurologist, who prescribes and monitors Trevor's medication, to attend the mediation; they also asked Trevor's primary pediatrician to attend. Both physicians agreed to come because they thought it was important to establish with the school a mechanism for ongoing communication about and evaluation of Trevor's progress. Both physicians strongly believed that Trevor should be placed back in regular fourth grade in his neighborhood school, with the classmates he had been with since first grade. The neurologist believed that knowing more about a typical day in regular fourth grade, and the expectations for Trevor within that day, might influence his prescription and timing of Trevor's medication. The neurologist also thought it was important for Trevor to have a behavior management plan in conjunction with his medication. The pediatrician believed he had good rapport with Trevor and his family, and a sense for how Trevor reacted to certain stresses and conditions. He noted that Trevor wanted to express how stigmatized and angry he felt at being placed in the special education fourth grade class, instead of in regular fourth grade with his friends; the pediatrician thus recommended that Trevor speak on his own behalf at mediation, and said that he would help facilitate the process for Trevor. He also said he would be willing to work with Trevor, the school psychologist, Trevor's family, and other team members to develop a behavior plan that was consistent for home and school. Trevor's parents agreed that these were important issues to raise at mediation, and thought that both physicians not only supported their concerns but wanted to work collaboratively with the school district. His parents further agreed that it was important to let Trevor speak at the mediation, as it was his future at stake.

Trevor's parents also asked Trevor's third-grade teacher to attend the mediation. She had told Trevor's parents during the PPT that she would have recommended regular fourth grade if support services could be worked out. She believed Trevor did not have ongoing, consistent supports in third grade, thus making it difficult for her to manage his inclusion in that class. The family wanted to stress to the school staff that when Trevor had previously been placed in regular education, he did not have supplementary supports, a curriculum plan, and a behavior management plan.

The family asked the advocate to attend as well. Since their last PPT meeting, the advocate had told Trevor's parents of a ruling in US District Court for the district of New Jersey; she said she would bring copies of the summary of the opinion for everyone at the mediation. In brief, the court defined inclusion as follows:

> "When a child with a disability is placed as a full member of a regular class with the provision of supplementary aids and services this is known as supported inclusive education."

The court also noted that:

> "An inclusive education program, where a child with a disability becomes a member of a regular class, does not imply that all special service delivery must occur within the regular class. For instance, resource room support, or other special services, may be delivered on a pull-out basis within the regular class, or a combination of the two, depending upon the needs of the child and the class as determined by the teachers and team involved."

The court ruled that any Individual Education Plans recommending self-contained special education classes with no meaningful opportunities for integrating the child with non-handicapped children violated IDEA. The school district also violated IDEA when it placed the student in a regular class for a portion of the day without supplementary support, without a curriculum plan, and without a behavior management plan. Trevor's parents were elated: this is exactly what they had been trying to explain to school district officials in terms of Trevor's initial placement in regular education.

Trevor's parents were comfortable with the group of professionals they had chosen to go with them to mediation. They believed that the group would support their goal of an inclusive fourth-grade placement for Trevor, and offer ongoing support to school district officials if they agreed to place Trevor back in regular education. Trevor's parents also thought it was important that the mediator and school district officials listen to Trevor voice his concerns. The family went to mediation with a positive attitude: they believed that it was important to try to negotiate and talk things through. If that didn't work, however, they were prepared to pursue this issue at the impartial hearing that is their right under the law.

DISCUSSION - ANSWERS

As Trevor's primary physician, evaluate the following:

According to the Individuals With Disabilities Education Act (IDEA) and Americans With Disabilities Act (ADA), what should be your role in addressing Trevor's educational needs?

- Collaborate with members of the PPT and other health care providers regarding Trevor's medical needs and the impact of these needs on his educational programming
- Clearly state Trevor's needs for medical intervention within the school, such as dispensing of medications
- Ascertain whether a comprehensive evaluation of Trevor's educational needs has been completed
- Determine the need for any assistive technology services or devices

Based on the information presented regarding Trevor's educational needs, does the Individuals with Disabilities Education Act afford Trevor the opportunity to participate in a regular education program?

- Yes

If, according to the IDEA, Trevor should participate in a regular education program, so, what part or parts of the IDEA specifically address Trevor's educational needs?

- Development of an IEP defining eligibility needs for special education programming and related services (Part A)
- Part B (for ages 3-21)
- Least Restrictive Environment component

What are the parental and family issues? How has the family appropriately asserted their right to have those issues taken into consideration when Trevor's IEP is developed?

- Parents feel that the self contained classroom is not benefitting Trevor because:

  a) It is not in the neighborhood school
  b) It excludes Trevor from the mainstream or regular classroom
  c) They see Trevor's behavioral difficulties increasing
  d) It complicates their childcare arrangements

- Less restrictive alternatives within the neighborhood school or the regular education classroom were not tried prior to placing Trevor in the self contained program

- Trevor may be in need of a comprehensive evaluation

- His parents do not feel supported by the school staff

- Trevor needs to have contact with non-disabled peers

- Parents appropriately requested a PPT meeting to review Trevor's program and sought support from their pediatrician, their neurologist, and an advocate

If Trevor were two years old, how might this process be different under IDEA Part H?

- Under Part H an IFSP would be written rather than an IEP, and would include a statement of the family's strengths and needs, the name of a service coordinator, and possibly steps for moving Trevor into the public schools at age three

APPENDIX A

Services Available for Eligible Infants and Toddlers under Part H of IDEA

Audiology

Case management services (service coordination)

Family training, counseling and home visits

Health services

Medical services

Nursing services

Nutrition services

Occupational therapy

Physical therapy

Psychological services

Social work services

Special instructional services detailed to the child's needs

Speech/language pathology

Transportation

Vision services

Assistive technology and devices

Parent-to-parent services

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Education Law ____________ Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

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Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

RESEARCH EFFICACY

The efficacy of a program is not always measured against quantitative norms.

Objectives:

Upon completion of this manual, you will be able to:

- **Define efficacy.**
- **Identify the variables which contribute to the efficacy of a program.**
- **Describe how efficacy might be measured in working with children who are at risk or those with disabilities.**

Research Efficacy

Efficacy is the positive effect that a program, strategy, or procedure has on the group at which it was aimed. In early intervention we are concerned with the efficacy of programs designed for children who may be at risk for developing problems due to environmental factors (Bronfenbrenner, 1975; Horowitz & Paden, 1973; Ramey, MacPhee & Yeates, 1984; Ramey, Yeates, & Short, 1984) as well as those at risk due to biological factors (Bricker, Bailey & Bruder, 1984; Dunst, 1985; Shonkoff & Hauser-Cram, 1987). Despite methodological limitations, the research done thus far support the effectiveness of early intervention programs with both groups of infants. Unfortunately, the accumulated data does not reveal which service delivery variables may be best suited for different types of family, children, and particular needs.

Principles of Efficacy

In early intervention and special education, efficacy does not necessarily mean a significant change in a child's Intelligence Quotient (IQ) scores. Rather, the efficacy of a program might be apparent in a number of other, possibly more important, areas, such as social behavior, adjustment to the family, or adaptive skills. A program also might produce gains in one area (for example, changes in the child) while not producing gains in other areas (for example, changes in the parents).

The program still could be considered effective, however, in these specific domains.

Demonstrating abilities in the "normal" range isn't necessarily a good measure for the progress of a child with disabilities; normal goals are in most cases beyond the reach of the child, or of current expertise and technology. Families of children with disabilities need to understand, therefore, that "normal" developmental goals may be inappropriate or unrealistic for their child. It is also important that the family have information regarding appropriate goals and the role that early intervention might play in attaining those goals. For example, a child with low muscle tone may not be able to roll over at the normal developmental age, but, with physical therapy provided through an early intervention program, the child may gain muscle tone and learn to roll over at a later stage of development.

Parents also should be aware that children with disabilities can develop **secondary handicapping conditions**, complications that result from the primary handicapping condition. For example, a child might suffer from low weight gain due to oral-motor difficulties, or muscle contractures or atrophy due to lack of movement. Early intervention services may prevent these additional complications from occurring.

According to the House Report (99-860)(1986) which accompanies the Individuals with Disabilities Education Act (P.L. 99-457), early intervention and early childhood special education programs can:

- enhance intelligence in some children;

- produce substantial gains in physical development, cognitive development, language and speech development, psychosocial development, and self help skills;
- prevent the development of secondary handicapping conditions;
- reduce family stress;
- reduce societal dependency and institutionalization;
- reduce the need for placement in special education programs once children reach school age; and
- save money for society and our nation's schools.

Future research may identify what specific variables contribute to efficacy in early intervention programs. Such variables may include child and family characteristics, program features, and goals and objectives (Guralnick, 1989).

Certainly, effective early intervention benefits the child not only directly but indirectly. By allowing parents to be parents, by encouraging them to nurture their child rather than take on a host of professional responsibilities (such as, occupational therapy and physical therapy), the parent-child bond can deepen. This bond is critical to the child's developmental process. An effective early intervention program may also help parents locate a parent-to-parent support network, through which they can explore their expectations for their child and her program.

FAMILY STUDY

Scotty is twenty-four months old and living at home with his mother, father, and eight month-old sister. His father works full-time and mother part-time. Scotty was born eight weeks premature and was hospitalized with a variety of problems for the first three months of his life. With the parents' permission, the discharge planning team made an early intervention referral on Scotty's discharge from the hospital, at age three months.

At twenty-four months of age, Scotty has many disabilities:

- Scotty has low muscle tone and does not walk or crawl
- He has feeding difficulties and problems gaining weight
- Scotty has vision problems
- Scotty has breathing problems which require frequent hospitalizations
- Scotty does not talk
- He has trouble sleeping through the night

Scotty has been receiving early intervention services both at his daycare and at the children's hospital. Currently, he has physical therapy three times a week, speech therapy two times a week, and occupational therapy two times per week, as well as visits from his early intervention teacher every other week. Scotty's schedule is as follows:

- Monday: daycare - 4 hours
  occupational therapy at daycare
- Tuesday: daycare - 4 hours

physical therapy at the children's hospital
speech therapy at the children's hospital

- Wednesday: daycare - 4 hours
  occupational therapy at daycare
  early intervention teacher every other week
- Thursday: daycare - 4 hours
  physical therapy at the children's hospital
  speech therapy at the children's hospital
- Friday: daycare - 4 hours
  occupational therapy at daycare

While at the doctor's office to have an ear infection of Scotty's treated, his mother and father begin discussing Scotty's lack of progress. Scotty's mother and father are tired and discouraged. After twenty months of early intervention therapy services, they perceive Scotty to be showing little improvement. He still doesn't crawl or talk, and already his little sister is beginning to make noises and talk. With Scotty not sleeping through the night, his sister needing their attention, and the demands of life in general, the parents don't see the point of continuing these therapies: they take up a great deal of time, and Scotty's parents don't see the results they thought they would.

DISCUSSION

As Scotty's pediatrician, how will you address the following?

What are the family's concerns?

What variables should you look at when defining the efficacy of Scotty's program?

How would you address the family's concerns and what would you recommend to them?

Scotty's family is measuring the effectiveness of this therapy against his sister's progress. How would you help develop a program for Scotty in which the parents can better see his progress?

How could you help the family to understand what expectations are realistic for Scotty?

RESOLVE

Clearly, Scotty's parents are questioning the effectiveness of the early intervention programming he is receiving. Despite the services of the physical therapist, occupational therapist, speech therapist and early intervention teacher, the parents feel that Scotty is making no progress, particularly in crawling and talking. The physician is aware of the stress and disappointment Scotty's parents are suffering; she asks them what their expectations are, and why they think that Scotty is not making progress.

Scotty's parents reply that after twenty months of intervention, they expected him to be crawling and to have a few basic words such as mommy, daddy, and juice or milk. They are also concerned and confused about why these goals haven't been met. The physician suspects that Scotty's parents have not been given clear expectations by the early intervention service providers, and that the services may not be well coordinated; she also wonders if the parents have enough emotional support.

The physician suggests that Scotty's parents request a meeting with the early intervention team, and says that she also will attend. The meeting is thus scheduled with the occupational therapist, physical therapist, speech therapist, daycare teacher, physician, and Scotty's parents. Each of the service providers discusses how he or she sees Scotty's progress, and redefines the goals toward which he or she is now working. The parents realize that their expectations had been too high and that they had not recognized the progress Scotty had made since early intervention began. The physician observed that Scotty's parents were having a hard time emotionally, and asked about resources to provide Scotty's parents with more support. The physical therapist told them about the parent-to-parent support network and said he would call the parents with the name and phone number of a person whom they could contact.

DISCUSSION - ANSWERS

As Scotty's pediatrician, how will you address the following?

What are the family's concerns?

- Scotty's progress is not what the family expected
- Early Intervention is not effective
- Scotty's parents feel stressed and discouraged

What variables should you look at when defining the efficacy of Scotty's program?

- Improvements in Scotty's verbal skills and his physical development (muscle tone)
- The adjustment of the family
- Changes in Scotty
- Weight gain
- Effectiveness of early intervention program in terms of the gains Scotty has made and in preventing secondary handicapping conditions from developing
- Communication among early intervention team and between service providers and the family

How would you address the family's concerns and what would you recommend to them?

- Have parents contact service coordinator to convene early intervention team meeting
- Revise the Individual Family Service Plan
- Explore additional support services for the family

Scotty's family is measuring the effectiveness of this therapy against his sister's progress. How would you help develop a program for Scotty in which the parents can better see his progress?

- Look at individual growth instead of developmental milestones
- Define where Scotty is now and what the next step is in his progression of development
- Focus on skills he has acquired (for example, social development as well as physical development)

How could you help the family to understand what expectations are realistic for Scotty?

- Look at individual growth instead of developmental milestones
- Define where Scotty is now and what the next step is in his progression of development
- Focus on skills he has acquired (for example, social development as well as physical development)

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Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Research Efficacy Date ____________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

ROLE OF OTHER DISCIPLINES

All disciplines have expertise which are equally important in developing a service plan for a child.

Objectives:

Upon completion of this manual, you will be able to:

- **Define special education and related services.**
- **Identify the roles of other professionals who may provide related services to an infant or child recieving special education.**
- **Describe and apply the components of a successful integrated therapy model.**

Because all children have different cognitive, physical, and psychological characteristics, they all require educational programs designed to meet their unique needs. Children ages 3 - 21 who have disabilities are entitled to special education and related services to meet their individual needs through P.L. 101-476, The Individuals with Disabilities Education Act (IDEA). Part H of IDEA also provides early intervention services for eligible infants and toddlers and their families.

Special Education and Related Services

Designing intervention programs to meet the educational needs of children with disabilities is a complex process; no one person has the skills, or knowledge adequate to do this. Rather, many professionals (for example, special education teacher, speech therapist, and physician) and the family must work together as a team to provide information, make decisions, and perform all the functions associated with delivering special education and related services. In order to avoid confusion and the fragmentation of services, it is essential that this team of people work collaboratively to plan, coordinate, and implement the services needed for each child. They will need to communicate with one another, share their expertise and skills, make joint decisions, and most important, coordinate their service delivery efforts.

Special education and related services are defined in P.L. 101-476 as:

Special Education:	Specifically designed instruction that is developed by a team to address the individual educational needs of the child. It is provided through a child's Individual Family Service Plan (IFSP) or Individual Education Plan (IEP). The Special Education Teacher provides the environment, activities, equipment, and methods/interventions to facilitate a child's development/education.
Related Services:	Include transportation and developmental, corrective, and other supportive services needed to assist a child with a disability and his/her family to benefit from special education.

Thus, each child may receive, in addition to a program of specialized instruction (special education), any one or a combination of the following related services, as stated on the IFSP or IEP: audiology or hearing services, medical services, occupational therapy, physical therapy, psychological services, school health services, speech therapy, social work, and vision services. Each person providing special education or one of these related services to a child with disabilities has a role specifically related to their discipline.

Roles of the Professionals

Each of the related service professionals listed above has training and expertise in his or her discipline, and each, acting within that discipline, contributes to or provides services to the education of children with disabilities. Their roles are described as follows:

Aide:	A person assigned to work directly with a child or in the same classroom to help meet educational needs, implement goals, and provide physical assistance to the child (for example, an aide might help implement a child's toilet training program).
Audiologist:	Evaluates hearing, provides rehabilitation when appropriate, and assists the team in understanding the nature of a child's hearing loss and how it may affect the child's development. An audiologist can offer strategies to help compensate for the hearing loss when communicating or listening to others (for example, ask the classroom teacher for preferential seating so the ear in which the child has hearing faces the teacher and not the window). Audiologists can recommend, monitor and instruct others in the use of hearing aids and auditory trainers.
Nurse:	Interprets and supports the child's medical and/or healthcare needs. Assumes responsibility for establishing a medical management plan which may affect the child's therapeutic and educational programs.
Occupational Therapist (OT):	Traditionally focuses on developing therapeutic methods to aid in activities of daily living, such as eating, dressing, and writing. Occupational therapists assist the team in adapting the home and school environment so a child can participate as independently as possible (for example, the OT might adapt a spoon handle to make it easier for a young child to grasp and hold).
Physical Therapist (PT):	Traditionally focuses on muscle tone, positioning, and helping a child to walk or become mobile with or without adaptive equipment (for example, walker, braces, or wheelchair). Physical therapists assist the team in determining appropriate programs for promoting motor skill development.

Physician:	Provides primary health care and specialized medical care to the child, including both diagnostic and treatment services. Physicians may also be a source of referral to other professional services or resources, such as therapeutic or psychological services, early intervention, or special education.
Psychologist:	Administers psychological assessments to children and interprets their findings to the team. In some settings, psychologists may also provide clinical services or counseling to children and families. Psychologists also develop behavior modification programs to implement in the home and/or school.
Social Worker:	Provides a link to services which support the family's well-being and needs. They play a diverse role, from direct counseling to helping families access community resources for financing, recreation, or community support (for example, respite services, food stamps, home nursing services, parent-support group).
Speech/Language Pathologist:	Evaluates a child's communication abilities. May address the production of speech sounds, including evaluation of the mouth, breathing, oral muscle control, and articulation. Speech/language pathologist is also responsible for developing alternative communication systems for children who are non-verbal (for example, sign language, or picture communication boards). The pathologist assists the team in developing interventions to improve communication skills.
Vision Specialist:	Develops adaptive equipment or programs to improve vision or use existing vision as much as possible. The vision specialist participates in the design of programs to teach independent living skills and mobility training to children who have visual impairments.

Integrated Therapy Model

Special education and related services for children with disabilities should be provided within the context of natural environments (for example, home, day care, nursery school, kindergarten, third grade) and incorporated into natural routines. Related service professionals may provide the service themselves, or they may train and consult with other service providers (for example, parents, regular education teacher, nursery school teacher) to provide the service.

Direct therapy occurs when the therapist works directly with the child on an individual or group basis in the context of natural routines. Direct therapy includes assessment, intervention, implementation, and evaluation. **Indirect therapy** involves training others to perform specific interventions and then monitoring the performance of those interventions on a continuing basis. For example, physical therapist might teach the nursery school teacher how to facilitate rolling for a young child unable to crawl, in order for the child to reach a favorite toy during free play: the therapist cannot be in the nursery school room all the time but the child needs to practice rolling, for mobility during naturally occurring routines. Thus, the physical therapist is providing indirect therapy to the child by training the teacher to implement interventions.

An integrated therapy model is the most efficient and natural way to provide children with disabilities with special education and related services, within natural environments. The integrated therapy model requires a team approach that emphasizes **role release** and indirect therapy services. Role release means sharing and exchanging certain roles and responsibilities among team members. All team members have specific skills and information they can share with others; in role release team members release some functions traditionally associated with their individual disciplines.

The success of an integrated therapy model requires that the team members (for example, special education teacher, speech pathologist, physician, physical therapist, nurse, and parent) work together on an ongoing basis to plan, implement, and monitor the delivery of services to the child. The ingredients necessary for the successful collaboration of professionals form different disciplines are:

- **Attitudes** of team members (their willingness to share information and skills)
- **Accessibility** of the specialists (their availability for consultation and training)
- **Communication** (the specialists reduce their use of jargon)
- **Transmission** of information (the specialists pinpoint relevant information to share with other team members)

Teams should follow an integrated approach to program development and implementation. The special education and related services professionals must work **across disciplines** to share information about the child's program, and be willing to release their roles in order to integrate the goals and objectives of each discipline involved in a child's care. This ensures that a child's individual needs are addressed through a collaborative process within naturally occurring routines and environments.

FAMILY STUDY

Jenny is a fifteen year old single mother living at home with her mother and father. Jenny's mother and father have supported her decision to raise her baby, finish high school, and continue to live with them. They have also agreed to pay for child care when Jenny is in school, since they both work. Jenny's daughter, Maddie, was born prematurely, causing a variety of problems. Most significantly, she has severe vision loss, possibly, she is legally blind.

When Maddie was discharged after two months in the NICU, Jenny was pleased with her progress. Maddie appeared alert and active, and ate well. The discharge plan recommended follow-up opthamalogical exams to monitor Maddie's vision problems, and referred Jenny to an agency that provides early intervention services for infants with blindness/low vision. Since the hospital is about 80 miles from Jenny's rural home, it is very difficult for her to make weekly follow-up appointments. The hospital agreed to have Jenny make bi-weekly visits to her pediatrician, whose office is in a nearby town and who has treated Jenny since she was a child, for follow-up services. The pediatrician, however, has not had any experience with children who have severe vision impairment, nor with early intervention or special education services.

DISCUSSION

As Maddie's primary pediatrician, evaluate the following:

How do you see your role in this situation ?

How do you see your role as Jenny's pediatrician ?

How do you see your role as Maddie's pediatrician?

What qualities do you feel the early intervention program should have, to best meet both Jenny and Maddie's needs?

What other professionals do you think Maddie will need the services of in her early intervention and later special education plan?

What do you need to know to feel more competent to treat Maddie now and in the future?

RESOLVE

The pediatrician met with Jenny and Maddie in his office. He believed the first step should be an informal discussion with Jenny to see how she was adjusting to all the changes in her life - physically, mentally, and emotionally. He thought it was important to see both his patients in a comfortable, non-threatening environment so he could get a sense of how Jenny interacted with Maddie. Next, the doctor asked Jenny if she had any questions about Maddie, such as her stay in the NICU, her vision problems, or general developmental concerns associated with premature births. Once this was done, the pediatrician let Jenny know that he felt very capable treating any of Maddie's medical problems, but that visual impairments was a new specialty for him. They would need to work together, and consult and learn from others who had more expertise in this field.

Next, the pediatrician discussed finding an early intervention program for Maddie. He asked Jenny where she would like Maddie to receive these services and discussed her options: home-based services or center-based services. Jenny said that a neighbor who had a little playgroup for babies and toddlers was willing to keep Maddie while Jenny went to school. Since Jenny wanted to place Maddie in a family daycare situation, the pediatrician understood that more people would need to learn about Maddie's visual impairments. He called the State Department of Education to get information about services available for children with visual impairments. He then gave Jenny the name of the agency to contact and wrote a referral for services based on information from the hospital. With Jenny's permission, he also made copies of any medical documents he felt the agency might need in order to start services for Maddie.

Within a month, Maddie was given an evaluation, by an early intervention team, which determined her to be eligible for early intervention services in the family day care. The evaluation recommended that she receive physical therapy and instruction from a vision specialist (a teacher for the visually impaired), for one hour twice a week. Once Maddie's program was under way, the pediatrician asked Jenny if the physical therapist and vision specialist might use one of their therapy sessions to meet with him in his office to help him better understand how to provide Maddie with care that is sensitive to her visual impairment.

By Jenny's arrangement, the pediatrician met with Jenny, the physical therapist, and the vision teacher. The group believed this meeting was a good opportunity to exchange information and share their expertise with one another, in order to coordinate their service delivery efforts. The physical therapist explained that babies with visual impairments or blindness often seem to dislike being picked up: they may arch their backs, become stiff, or seem to push away. Both Jenny and the pediatrician had seen this reaction in Maddie before. The physical therapist explained that visually impaired babies are often quiet and still much of the time because they are listening to what is going on around them; their reaction to being picked up is related to this keen attention they are giving the world. If they are safe and intent on listening, and suddenly finds themselves being moved around in mid-air, it is natural for them to get upset. The physical therapist suggested giving some kind of warning that Maddie is going to be picked up:

first talk softly, then add a touch of the hand, and then finally, pick her up. The vision specialist also told Jenny and the pediatrician that babies with visual impairments/blindness usually do not receive the visual cues that would warn them of impending discomfort or unpleasant situations such as having their temperatures taken, getting shots, having cold stethoscopes placed on their chests, or wiping their faces and noses. She suggested using a signal, such as, a gentle knock before the activity, to help prevent Maddie's generalized withdrawal, and to keep Maddie receptive to positive human contact. The team members thought that this type of information-sharing was essential to best meeting Maddie's needs; they believed they should meet on a bi-monthly basis to ensure continuity as Maddie grows and her needs begin to change. Jenny suggested including the family daycare teacher, although it would be hard for her to get away. The therapists then said they would share their information with the teacher when they went to the day care. The pediatrician suggested they rotate the meetings, and said he would try to visit the day care.

DISCUSSION - ANSWERS

As Maddie's primary pediatrician, evaluate the following:

How do you see your role in this situation?

- To learn about the integrated therapy model as well as Maddie's individual needs
- To remember that Jenny is still a patient, as well as her daughter, Maddie
- To give Jenny the respect shown to all other parents

How do you see your role as Jenny's pediatrician?

- To ensure that Jenny is adjusting physically, mentally, and emotionally to all the changes in her life
- To make it clear to Jenny that she can ask any question at all, either regarding herself or Maddie

How do you see your role as Maddie's pediatrician?

- To consult with a vision specialist to learn about the particular needs Maddie may have
- To refer Maddie to an early intervention program
- To collaborate with Jenny and other professionals to provide the best possible care for Maddie

What qualities do you feel the early intervention program should have, to best meet Jenny and Maddie's needs?

- A vision specialist must share his or her extensive knowledge about visual impairment
- The physical therapist must have knowledge of visual impairments
- The professionals must respect Jenny as a parent, while being sensitive to her youth
- The professionals must collaborate with Jenny and each other to formulate an IFSP which will maximize Maddie's abilities and assist the family

What other professionals do you think Maddie will need the services of in her early intervention and later special educational plan?

- A vision specialist
- A physical therapist with knowledge of visual impairments
- A social worker

In the future she will need the following professionals in addition to the above:

- Special education teacher
- Psychologist

What do you need to know to feel more competent to treat Maddie now and in the future?

Now:

- Maddie's current age and level of development
- The family needs

Future:

- Maddie's progress, in other areas beside the medical
- The content of IFSP meetings

REFERENCES

Individuals and Disabilities Education Act (1991). P.L. 102-119. (20 U.S.C. Sections 1400-1485.

Early Intervention and Special Education in Connecticut

Training Manual Evaluation

Name of Manual Role of Other Disciplines Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

CURRICULUM DEVELOPMENT

The basic components of curriculum design should include health care needs to positively affect the development of programs for infants and children with disabilities.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe curriculum design as it pertains to the early intervention and special education of children with disabilities.**
- **Define assistive technology and list examples.**

Children learn and develop at their own pace. A special education classroom or early intervention program, therefore, is structured to meet the varying needs of all the children it serves. The teachers or intervention team staff, and parents, develop a curriculum for each child. The curriculum is an organized set of activities designed to achieve the learning goals set for each child. It outlines both the **content** to be taught and the **methodology** to be used, and thus it is the framework within which teachers and early intervention teams (for example, families, special educators, speech therapists, daycare teachers) work to meet the individual needs of the enrolled children. A curriculum should contain appropriate planning for each student's growth and development within the group structure of the classroom. It should be chosen with a thorough understanding both of the philosophy of child development and of its implications for the child's individual learning needs.

The Individual Family Service Plan (IFSP) and the Individual Education Plan (IEP)

The curriculum for a learner with disabilities is contained in the Individual Family Service Plan, for children up to age three, or the Individual Education Plan, for children age three to twenty-one. The team developing the curriculum should keep the abilities, goals, concerns, and preferences of the learner in mind, and seek to implement the curriculum within the routines and activities of naturally occurring environments. The educational team for students with disabilities (for example, family, special education teacher, regular education teacher, and related service professionals) should collaborate on implementing curriculum goals and objectives; this collaboration will benefit the "whole" child and help ensure that he or she will use in other settings the skills learned in one.

An effective curriculum should address a wide range of the child's interests, and abilities, and provide a variety of activities and materials. The complexity of the work, and the challenges to the children and youth will increase as they master the initial skills targeted in their goals and objectives as stated in the IFSP or IEP.

Curriculum Design

Developmentally Appropriate Practice

Special education programs often use an eclectic approach to curriculum development and service delivery. However, the specific program components of any individual curriculum should be grounded on current theories of development, cognition, behavior, or ecology. One approach to curriculum is to consider it in terms of "Developmentally Appropriate Practice" (Bredekamp, 1987). Developmentally appropriate programs are designed to meet the needs of individual children. The concept of developmental appropriateness has two components: age appropriateness and individual appropriateness.

Age Appropriateness:

> **Research indicates that there are predictable sequences of growth and change that occur in all areas of development. Knowledge of the typical development of children assists teachers to plan appropriate experiences and prepare the learning environment. Examples may include a young preschooler with severe disabilities who needs to have sensory experiences and can be helped to play at a sand or water table with peers; a twelve year old with severe disabilities who needs sensory experiences and could be helped to use sand, water, and clay to make a topographical map with peers in his/her seventh grade social studies class.**

Individual Appropriateness:

> Each child is, of course, unique. The curriculum and the adults' interactions with the child, therefore, should respond to the child's individual needs. Each child's experiences with peers, adults, and learning materials (such as, toys, books, and computers) should match the child's developing abilities, and expand his/her interest and understanding. The goals for each child should be reached through activities that are child-initiated and directed. The child's learning should not be impeded by adult-established concepts of completion, success, and failure.

Natural Environments

Although a specific disability may primarily affect one part of a child's development (such as vision), other developmental domains also are likely to be affected. A combination of goals is necessary, therefore, to ensure a natural teaching setting and an efficient teaching approach. For example, a child with low muscle tone in the trunk area can work a puzzle with a peer, while a physical therapist helps with muscle control: this situation integrates, the child's motor, social, and cognitive development into one activity, rather than treating them in isolation. This approach improves on past practices in special education, in which professionals concentrated solely on the primary effects of a specific disability; it also allows special education and related services (such as physical therapy) **to be integrated into the child's learning experiences through naturally occurring routines and activities** in the home, nursery school, elementary school, or high school. Naturally occurring routines may include storytime, dressing, playtime, reading groups, art, gym, and so on. This process is called "activity-based instruction."

Activity-Based Instruction

Activity-based instruction embeds the teaching of many skills during one routine/activity and the teaching of one skill across many routines/activities (Bricker & Cripe, 1992). This type of instruction uses naturally occurring events to teach functional and broadly applicable skills. For example, a child can work toward motor, communication, social, and cognitive learning objectives during the routine of free play, while bathing dolls at the water table. This activity can promote communication with another peer (as in, "I want the soap"), social skills (as in, taking turns with the soap), motor skills (for example, reaching and grasping for the soap or washcloth), and cognitive skills (e.g., problem-solving by finding something with which to dry the dolls). Also, one goal in the area of communication (for example, choice-making through pointing) can be taught in a variety of routines: the child can point to a favorite cracker during snack; point to his/her choice of colors for an art project; and point to a favorite book during storytime.

Assistive Technology

A new, exciting, and important addition to curriculum planning for children with disabilities is **"assistive technology,"** legally mandated in The Individuals with Disabilities Education Act, **"assistive technology service"** is defined as:

> "...any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device..."[20 U.S.C. 1401 (a) (26)].

The term "**assistive technology device**" is defined as:

> "... any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified or customized, that is to increase, maintain or improve functional capabilities of individuals with disabilities." [20 U.S.C. 1401(a)(25)].

Assistive Technology, then, means access to the use of a classroom computer for a child who cannot write, or providing a child who cannot talk, but who can read, with a touch talker or picture board for communication.

FAMILY STUDY

Marissa was born at a local community hospital. When she was one month old her family noticed waxy-looking pimples on her arms and legs. Marissa's pediatrician referred her to the dermatologist on staff. The results of a biopsy indicated an extremely rare and unusual genetic disorder.

- At six months, Marissa developed a severe seizure disorder.
- At nine months, Marissa's teeth began to grow in abnormally.
- At one year, Marissa's family had her evaluated for early intervention services. The assessment team determined that she was significantly delayed in her language, motor, social, and cognitive development.

Marissa's family enrolled her in a local early intervention program. She received a home-based intervention program for the next twelve months. Then, at twenty-four months, the early intervention team (family, special educator, speech therapist, physical therapist, and pediatrician) decided to enroll her in a nursery school in the community for three days a week. The team felt the time had come to move Marissa's educational services from home into an inclusive, early-childhood program. In this natural environment Marissa could interact with other toddlers and enlarge her learning environment. The early intervention team decided on a neighborhood nursery school philosophically committed to including all children. The team chose a mixed two and three-year-old group and determined that Marissa would receive the support services of special education, speech therapy, physical therapy, and occupational therapy.

The early intervention team met to develop, update, and prioritize the goals and objectives on the Individualized Family Service Plan (curriculum) for Marissa's nursery-school class - - her new learning environment. They discussed the progress she had made thus far, her current abilities, and areas to target for learning. They prioritized the areas to focus on with her: communication and mobility.

Marissa is unable to move independently. The physical therapist believes that Marissa needs this independence, and suggests she use a motorized, adapted go-cart. The other priority set for Marissa is communication skills: although Marissa is able to vocalize, she does not communicate by speech. The speech therapist thinks that assistive technology, in the form of a touch talker, will benefit Marissa. The touch talker will allow her to communicate expressively with her family, peers, and teachers.

Both the priorities for Marissa's individualized curriculum require assistive technology: the touch talker for communication and the motorized go-cart for mobility (see Appendix A for other types of assistive devices). The family senses resistance from the early intervention team and they decide to ask their pediatrician, who has supported Marissa's placement in a natural environment, for a letter strongly recommending that these two devices be listed on her IFSP in order to increase and improve her functional capabilities as a learner.

DISCUSSION

As Marissa's primary pediatrician writing this recommendation, how would you answer:

What is assistive technology?

How does assistive technology relate to Marissa's needs and to the development of her curriculum or IFSP?

How can these devices (the motorized go-cart and the touch talker) be used in the routines of Marissa's nursery school program? (refer to appendix B)

Who could most appropriately help Marissa learn how to use these devices?

What are the specific skills Marissa will be working on, in using these devices?

RESOLVE

The pediatrician is very familiar with Marissa's history, having followed her since infancy. He supports the inclusive environment at the preschool. He has spoken on the phone to the various service providers (speech therapist, physical therapist and occupational therapist, special educator, nursery school teacher, and family) to get specific information for his letter of recommendation to the early intervention program. The team members have informed the doctor that Marissa will need to use a touch talker and motorized go-cart to help implement her curriculum for improved communication and mobility. These are not luxuries but necessities, to which she is entitled by law.

The pediatrician asked the team to send him an activity-based schedule reflecting the use of these devices within Marissa's daily activities at the nursery school. The team sent him a list of specific objectives that Marissa was working on for communication and mobility and a sample of how and when these objectives would be taught (see Appendix B Activity Based Schedule). The team indicated that the pictures they used on the touch talker would reflect the routines, vocabulary, peers, teachers, and family members in Marissa's school and home environments.

The pediatrician reviewed the Activity Based Schedule and agreed that Marissa needed assistive technology to accomplish her Communication and Mobility objectives. Without these devices she would be dependent on others for communicating and for moving around in her environment. This was not acceptable. Thus the assistive technology is an integral part of her curriculum and needs to be written into her IFSP.

DISCUSSION - ANSWERS

As Marissa's primary pediatrician, writing this recommendation, how would you answer:

What is assistive technology?

- Devices and services that enable people with disabilities to function optimally in their natural environments

How does assistive technology relate to Marissa's needs and to the development of her curriculum or IFSP?

- In order for Marissa to be able to participate in the learning environment, she may need assistive devices and/or services
- Marissa's need for assistive technology must be incorporated into the IFSP or IEP in terms of methodology and activity-based instruction
- Without assistive technology Marissa's social development would be limited

How can these devices (the motorized go-cart and the touch talker) be used in the routines of Marissa's nursery school program? (refer to Appendix B)

- The motorized go-cart will enable her to move around the classroom independently
- The touch talker will enable Marissa to communicate more efficiently with peers and adults and will allow her to demonstrate what she as learned
- The devices will both enhance her socialization with peers and her independence

Who could most appropriately help Marissa learn how to use these devices?

- This is to be determined at the IFSP meeting
- Most likely the physical therapist for the go-cart and the speech and language therapist for the touch talker
- Whoever facilitates the use of these devices, they will need to do so in collaboration with the teachers, other service providers and the family

What are the specific skills Marissa will be working on, in using these devices?

- Communication
- Mobility
- Socialization
- Independence

APPENDIX A

Partial Adaptive Equipment List

Communication Devices

- Adapting Switches
- Artificial Voices
- Pointers
- Nonoral Communication Systems (i.e., touch talker)
- Scanners

Items to Facilitate Daily Care

- Bath Seats
- Lifts
- Adaptive Clothing

Mobility Aids

- Scooter Board
- Wheelchair
- Crutches
- Canes
- Walkers
- Reciprocating Walking Brace

Orthopaedic Appliances

- Adjustable Prone Board and/or Stander
- Hand Splints (Static and/or Dynamic)
- Ankle Foot Orthosis (AFO)
- Limb Prosthesis

Positioning Devices

- Bolsters
- Modified Furniture
- Wheelchair Tray

APPENDIX B

ACTIVITY BASED SCHEDULE

Pre-School: ABC Pre-School Name: Marissa

	Domain					
Nursery School Schedule of Activities	Gross Motor	Fine Motor	Language	Cognition	Self-Help	Social/ Emotional
Arrival			Marissa will use touch talker to touch two pictures "Hi" and peer's name for greeting		Marissa will use touch talker to press two pictures "I want" and bathroom	
Free Play (blocks, housekeeping, water table, art corner, large toys				When asked where do you want to play, Marissa will use touch talker to press two pictures; play and her choice		
Art			Marissa will use touch talker to indicate her choice of colors for art project.		Marissa will use touch talker to indicate "I want" and help.	
Snack		Marissa will use go-cart forward from center of room to snack table to carry snack to table.				
Outdoor or Indoor large group play	Marissa will use go-cart to move joystick forward to go to slides.					Marissa will move go-cart forward in playground to give peer a ride.
Story Time			When asked to choose a story, Marissa will press touch talker to indicate choice "I want" bears.			
Dismissal						Marissa will use touch talker to say good-bye to a friend.

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Bricker, D., & Cripe, J.. (1992). An activity based approach to early intervention. Baltimore, MD: Paul H. Brookes Publishing Co.

Individuals with Disabilities Education Act (1991). P.L. 102-119. [20 U.S.C. Sections 1400-1485].

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Curriculum Development Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
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I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
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NATURAL INSTRUCTIONAL ENVIRONMENTS

Recognize that the environment in which intervention takes place has an impact on the effectiveness of that intervention

Objectives:

Upon completion of this manual, you will be able to:

- **Describe how education for children with disabilities in the "least restrictive environment" is protected by law.**
- **Describe the goal of inclusive education in natural environments.**
- **List the benefits of inclusion for children with disabilities.**

Legal Issues

The school-age child with disabilities was given the legal right to attend public school systems in 1975 through the passage of P.L... 94-142, **The Education of the Handicapped Act.** This landmark legislation mandated the development of Individualized Educational Plans (IEPs), allowing a student with disabilities to receive a free, appropriate education. In 1986, P.L.... 99-457 expanded the education mandate for the child with disabilities to include children from birth to age 21. The Education of the Handicapped Act was renamed **The Individuals with Disabilities Education Act (IDEA)** in 1991; the law now placed an increased emphasis on providing special education services to the child in the **least restrictive environment.** That is, to the maximum extent appropriate, schools must provide special education services to the child in a classroom with the child's non-disabled peers. The child is removed from such a setting only when the severity or nature of his or her disability is such that the child cannot be educated in regular classrooms even with supplementary aids and/or services. When a child receives a majority of his or her services outside of the regular classroom, the intent of the law is to return that student to the least restrictive environments as soon as possible. Additionally, schools must provide a continuum of services, not just one solution or placement option.

To ensure equal access for the student with disabilities within the public school systems, The **Americans with Disabilities Act** of 1990 (ADA) stipulates that schools provide such public accommodations as ramps and accessible stalls in school restrooms for the student with mobility limitations. The law also requires that the student have equal access in learning situations, under the term **"reasonable accommodation".** Under ADA, for example, it is reasonable in today's computerized society for a student with limited mobility of his or her hands to be provided with a computer.

For children under the age of three an additional consideration is the **natural instructional environment.** In states that participate in Part H of IDEA (early intervention for infants and toddlers), the infant or toddler must receive services in his or her natural environment, in accordance with the Individual Family Service Plan. Natural environments may include the home or settings in which children without disabilities participate. Part H also requires transition planning to aid in the movement of the child from early intervention programs to special education programs within the local school district. Transition planning should begin three to six months prior to the child turning three.

The concept that all children can be taught together while still meeting each child's individual needs has required a sometimes difficult adjustment for many special education, early intervention, and "regular" education professionals. In thinking back to our own school experiences, the majority of us were exposed to traditional teaching methods, curricula, and learners. The child with disabilities was rarely a part of our educational experience, and in many schools there was little variation in teaching style or adaptation to individual differences. School officials usually assumed that all children at a given grade level should meet the same skill levels and master the same curriculum.

Inclusive Education

The goal of inclusive education in natural environments is to ensure that each child is accepted as an equal classroom member, recognized for his or her abilities, and provided with an appropriate educational program and any supports necessary for the child to be a successful learner (Stainback & Stainback, 1992). This pertains to the child who has been labeled severely or profoundly mentally or physically disabled, disruptive, chronically ill, medically fragile, atypical, gifted, or at risk. All service providers and educators need to incorporate into their philosophy about education the value of providing the child with disabilities the opportunity to learn in natural environments/inclusive settings. Some of the major benefits of inclusion are:

- The child with disabilities who is provided with the necessary support services will be able to participate in and have the same types of experiences as children without disabilities, while still having individual needs met
- Opportunities in natural environments increase the likelihood that a child with a disability will learn how to interact with the real world: no child should be denied this opportunity
- Research shows that the early years of life are critical for learning and growing. Natural environments, such as integrated early childhood programs, are better suited to meet the needs of each child, and to enhance the child's potential
- Early childhood programs provide natural environments that are flexible, open, challenging, accepting, growth-producing, and individualized
- Children learn from their peers

- Natural environments (for example, daycare, preschool, kindergarten, regular elementary, middle and high school grades) provide broader options and choices in all areas (play, social competence, language, curriculum) than segregated classrooms focused on children with delays or disabilities

FAMILY STUDY

Jason is 36 months old and lives at home with his parents and four siblings. His father is in the construction business and works on and off, depending on the availability of jobs; he also plays in a band on weekends. The older two children have afterschool jobs and help contribute to the family income. Jason's mother is not now working.

Jason was born six weeks premature and was hospitalized for two months after birth because of a prenatal viral infection. At birth, Jason experienced repeated episodes of respiratory distress and severe feeding difficulties. At 36 months of age, Jason has:

- Very stiff muscles
- Vision problems
- Severe brain damage
- A communicable disease: people in contact with him have to be cautious
- A gastronomy tube for feeding
- He requires occasional suctioning at home, for which the family has a machine
- Jason is often irritable and cries frequently
- Jason uses adaptive seating and undergoes a variety of positioning techniques to minimize his discomfort and facilitate some independent arm movement for playing and exploring toys
- Jason is able to let his family know when he is uncomfortable by crying; he lets them know when he is happy or enjoying them by vocalizing and smiling

Jason receives his medical care at the city hospital and goes to specialty clinics (for example, for adaptive equipment and orthotics) at the children's hospital . The family pediatrician has been caring for the family for 17 years. The family feels comfortable with him and found him to be helpful, informative, and supportive when Jason was born. The pediatrician currently coordinates all of Jason's medical care.

Jason has been receiving early intervention services through a state early intervention program since he was six months old. The early intervention program provides both direct services and indirect consultation to infants and toddlers in the home. As required by law, the program also provides these services to children, usually from 18 to 36 months, in natural community environments such as daycare and/or nursery school programs. The decision about where a child should receive his or her services is made by a team during the Individual Family Service Plan (IFSP) process, with the family, early interventionists, and any other people who are an integral part of the child's life (for example, nurse, physician, grandparents, baby-sitter) participating.

Currently, the early intervention program has been providing Jason with services three mornings a week in his neighborhood nursery school. He receives onsite services from a special education teacher, as well as occupational therapy and speech therapy once a week. He receives physical therapy at home three times a week through a rehabilitation program. Through the Board of Education Services for the Blind (BESB) a vision teacher provides Jason with consultation services once a month at the nursery school. Many of Jason's medical needs are monitored through nursing services provided by the early intervention program. A nursing consultant goes to the nursery school three mornings a week, while Medicaid provides Jason with nursing in his home on the other two mornings. Both of these professionals give Jason the medical attention he needs, such as medication and suctioning.

Jason's parents believe he has been positively challenged through his early intervention services in this inclusive natural environment; they also think he has had wonderful opportunities for socialization and interaction with his peers in the community. Since Jason has been in a neighborhood nursery school, his mother has met some of the other mothers at gatherings and meetings; this contact has led to weekend playdates for Jason with some of his schoolmates. The children sometimes come to Jason's house, and sometimes Jason goes to their houses. Jason's mother is thrilled that the families she has met have been friendly, open, supportive, and non-judgmental. Jason's parents also think that much of what he has been able to accomplish (for example, moving his arms to explore toys, vocalizing to get attention, eating with a spoon, using assistive technology, and responding to other children) is directly related to his receiving services in the inclusive early intervention program at the nursery school. Jason's parents feel very strongly that they would like his future learning experiences to continue in this direction.

Since Jason is 36 months old, the responsibility for his program and service provision will transfer from the early intervention program to his local school district, and his parents and the professionals involved with him have began planning for this transition. Jason's parents would like the school district to continue providing his special education and related services in his nursery school, as has been done by the early intervention team. His parents have had meetings with officials of the school district, who have told them that the school district does not offer this type of service in the community, especially for youngsters with severe multiple disabilities. The district officials explained to Jason's parents that their special education preschool program is in the local public school, where Jason can be in a class with six other children. These children also have serious medical problems and are at Jason's level of functioning. The school district has a nurse at this program who can monitor Jason's medical needs full-time.

Jason's parents strongly believe that Jason should be given the opportunity to continue his education in a natural environment such as his nursery school. He has made wonderful progress there, and the early intervention team agrees strongly that Jason should continue to receive services in the nursery school. The early intervention team will support the family as it advocates this placement with the school district. The family pediatrician has also been pleased with Jason's experience in the nursery school. Jason's planning and placement team (PPT) meeting with the school district officials is scheduled for the following month. Jason's parents think that they should begin to plan for and seek solutions for some of the problems and barriers his severe disability and his medical problems seem to present to the school system. Jason's parents have made an appointment with the pediatrician with whom they are most comfortable, in order to solve some problems before the meeting.

DISCUSSION

As Jason's primary pediatrician, evaluate the following:

In what ways does Jason benefit by receiving his early intervention and related services in a natural environment such as the nursery school?

What are some of the medical problems Jason has that make the school district officials think they cannot meet his needs in a natural environment?

The family comes to you, the pediatrician, for help in solving some of the obstacles the school district officials are raising about Jason's medical concerns. What are some of the possible solutions? What strategies might you undertake?

RESOLVE

Jason's parents met with their family pediatrician to address some of the barriers the school district was raising to deny Jason educational services in an inclusive environment. The first concern the family shared with the doctor was that Jason would continue to need nursing support in his nursery school. The early intervention program was currently providing direct nursing care for Jason on the three mornings he was at nursery school, but when Jason transfers to the school district he will no longer be entitled to nursing care, since the funding source will change. The pediatrician examined Jason's nursing care situation: during the times when Jason was not in the nursery school (two mornings a week), he received nursing at home through Medicaid. Jason's home state allows Medicaid nursing services to follow the child. The pediatrician therefore realized that he could increase Jason's Medicaid nursing to five mornings a week, thus providing the service in the nursery school. This should eliminate any concerns the nursery school and school district officials have about monitoring and meeting Jason's medical needs.

Next, Jason's parents explained to the pediatrician that Jason was now entitled to receive his educational services five half-days a week through the school district. The pediatrician thought that for the time being Jason should continue to attend the nursery school only three days a week, as he was doing well both physically and emotionally, and as many "typical" three-year-olds attend nursery school on a part-time basis. Jason's mother agreed and was comfortable with this idea, especially since she enjoys having him at home the other two mornings. She will continue to arrange playdates for him with his friends.

The pediatrician also made suggestions for some of Jason's specific medical needs, such as suctioning and tubefeeding. He believed that Jason's educational planning team should consider interventions in the nursery school so as to decrease Jason's need for these services over time. He suggested, for example, that the speech therapist look at an eating program to increase oral motor development; he thought such a program could be implemented both at home and during snacktime in the nursery school. The family and professionals could eliminate the tubefeeding in school and concentrate on building up Jason's oral motor skills. The pediatrician said he would be willing to call the speech therapist to work out some possibilities.

The pediatrician also believed the physical therapist might be able to introduce some positions in the nursery school that would not interfere with Jason's play skills but that would facilitate postural drainage and thus reduce the amount of suctioning Jason needed during the morning. The pediatrician offered to call the physical therapist to discuss and plan some interventions.

Finally, the pediatrician agreed with the family's observation that Jason had made great improvement and gains in the inclusive nursery school environment; he believed Jason to be content, happy, growing, and learning in this environment, despite his complex medical needs. The pediatrician therefore agreed to write a letter to the school district, strongly recommending that Jason continue to receive his educational program and related services in the nursery school.

Jason's parents left the pediatrician's office with possible solutions and strategies, new goals, and a strong recommendation for inclusive education. The pediatrician had provided a solution to the nursing situation, which was the most critical barrier to Jason's remaining at the nursery school. He also looked at long-term strategies to reduce the medical care Jason needs. All of these solutions, strategies, and goals meant collaborating with the local school district and, most importantly, looking at ways to implement these interventions within the nursery school environment. And, finally, the pediatrician thought that a letter with his strong recommendation to maintain Jason in his current placement was important.

DISCUSSION - ANSWERS

As Jason's primary pediatrician, evaluate the following:

In what ways does Jason benefit by receiving his early intervention and related services in a natural environment such as the nursery school?

- Within the least restrictive environment, Jason would have access to the same broad range of experiences as his non-disabled peers
- It promotes acceptance and equality, as well as recognition of abilities rather than disabilities
- It complies with the law

What are some of the medical problems Jason has that make the school district officials think they cannot meet his needs in a natural environment?

- How to protect themselves and the other children from the communicable disease Jason has.
- Having to manage the feeding tube and Jason's need for suctioning, as well as, adaptive technology.

The family comes to you, the pediatrician, for help in solving some of the obstacles the school district officials are raising about Jason's medical concerns. What are some of the possible solutions? What strategies might you undertake?

- Set up a meeting with the physician, the family, and the current early interventionists to provide school officials with education and information regarding:
    - a) Jason's medical needs, and who can attend to them within the school
    - b) Precautions to take for the communicable disease
    - c) How current service providers have addressed these concerns
    - d) What has helped Jason be so successful in his current program

REFERENCES

Stainback, W., & Stainback, S. (1992). Schools as inclusive communities. In S. Stainback & W. Stainback (Eds.), Controversial issues confronting special education: Divergent perspectives. Boston, MA: Allyn and Bacon Publishing Co.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Natural Instructional Environments Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

SERVICE COORDINATION

Service coordination enhances the team's ability to meet the family's needs.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe service coordination.**
- **Describe how service coordination assists physicians treating children with disabilities or special health care needs.**

Families who have children with disabilities or special health care needs often face a fragmented, compartmentalized, and difficult to access system of services for their children. These services have been developed haphazardly, in response to social, political, economic, scientific, cultural, and other factors over the years, without the benefit of a strategic plan. In service coordination, this lack of planning, or organization, is addressed by one individual who is knowledgeable about the complete service delivery system and who is designated by the lead agency in early intervention. The function of the service coordinator is to assist families in finding and using the needed services and supports.

Service Coordination

Service coordination is a new way of planning services for children with disabilities and their families. In traditional case management, each service or agency (for example, rehabilitation, school services, health) had its own case manager to oversee the services provided by that particular agency, and the progress made with those services. These programs developed case management systems to address their own administrative convenience and efficiency, rather than to address individual family needs, and preferences within the community. The case manager often served as the gatekeeper, monitoring the use of resources within that agency. This was done with little or no input from the family and, consequently, these case managers were often ineffective in meeting the needs of families. As a result, a member of the family often assumed the role of service coordinator, planning and overseeing their own services and supports, even though she or he was not officially recognized in this role.

Service coordination replaces the concept of case management, under P.L. 99-457, for children from birth to three years of age. Under P.L. 102-199, Section 303.6, service coordination is broadly defined to include the following:

> "The activities carried out by a service coordinator to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards and services that are authorized to be provided under the state's early intervention program. Service coordination, also includes identifying, accessing, coordinating and monitoring other services which the child and family may need."

The intent of the law is for the service coordinator to help parents take charge of the issues that are important to them. The service coordinator is the single point of contact for the family and the service providers.

Referral Procedures

A referral for early intervention services can be made by parents, physicians, teachers, or other involved indivduals. To initiate a referral, call the number designated by the lead agency. Upon referral a trained service coordinator will be assigned to the family as provided by the law. In some cases the service coordinator is selected from the program or agency most directly involved with the child; in other cases the coordinator is independent of the early intervention programs, but knowledgeable about the priorities and concerns of this particular child and family. The service coordinator can also be the parent of a child with special needs. Part H stipulates that service coordination will be available at no cost to families with eligible children.

A family-centered model of service coordination requires that families be able to chose their service coordinators from a pool of trained service coordinators. Best practice dictates that this person should be neutral, that is, not providing direct service to the child and family.

Leaders in education, health, mental health, parent networks, and human services are enthusiastic about the potential of service coordination, as it will play an important role in a shifting from the traditional model of service delivery to a more individualized, collaborative and family centered system. Under such a system, integrated community-based services will be available to the children and their families. These families will be assisted and supported by a pool of trained service coordinators.

For physicians treating children with disabilities or special health care needs, the implications of service coordination are significant. The service coordinator will provide the physician with an easy way to have meaningful input into a child's overall care plan, for the service coordinator can integrate the child's health needs into the broad plan of care in the community. This system thus asssures the physician as well as families of easier access to the services and supports the child needs.

FAMILY STUDY

Lynn is two years old and is in a community daycare program. Lynn lives with her father, Al, and a nine-year-old sister. Lynn was delivered at 33 weeks gestation, following a car accident in which her mother was killed. Lynn's care involves many professionals and community resources. She receives her services through a variety of agencies, and often her father alone must coordinate and plan them.

Al works full-time as a salesman, and because of his schedule, he has difficulty attending meetings and scheduling appointments for Lynn. He often has to miss work and lose pay in order to meet all of Lynn's requirements. His sister lives nearby and helps out with some of the daily chores, like grocery shopping, but she feels that she is not knowledgeable enough about Lynn's health issues to take her to appointments or attend meetings for her. She does provide Al with a great deal of emotional support, however.

Last month, Lynn had two appointments with her pediatrician because of an infection, an appointment with her neurologist, an eye examination, a fitting for her wheelchair, an Individual Family Service Plan (IFSP) meeting, a visit from the DMR social worker, and a meeting with the case manager from the Home Health Agency. Each of these appointments was scheduled at a different time, on a different day. Al lost a total of 26 hours from work, without pay; his boss informed him that he could no longer take this much time off on a regular basis. Al is concerned that he must now choose between Lynn's care needs and his much-needed job.

To make matters worse, Al's insurance will no longer cover Lynn's occupational and physical therapy at Easter Seals, and may only cover some of the home health care which Al needs in order to work. He has discussed these issues with his social worker at DMR, but the social worker did not offer him any real assistance or solutions. Al then told Lynn's doctor that he would have to discontinue her therapy. He is also afraid he will lose his job if he loses the home health care, since the aide stays with Lynn before and after day care. Lynn's doctor is concerned that Al may not be able to continue to care for Lynn on his own.

Lynn's services include the following:

- home health care (32 hours per week)
- early intervention teacher visits (once per week at day care)
- occupational therapy (twice per week at Easter Seals)
- physical therapy (twice per week at Easter Seals)
- speech therapy (twice per week with a private provider)
- day care (five half days per week)
- case management services from Department of Mental Retardation
- respite funds from the Department of Mental Retardation
- case management services from the Department of Health Services
- benefits management from the insurance company
- social services from Easter Seals
- social services from the children's hospital
- case management from the nursing agency

- a minimum of three specialty appointments per month, including: (ophthalmology, neurology, orthopedics/cp clinic, pediatrics for numerous ear infections/colds, orthotics/adaptive equipment

DISCUSSION

As Lynn's primary pediatrician, evaluate the following:

What challenges do you see in coordinating services for Lynn?

What strengths does the family have which might assist those coordinating services for Lynn?

Who might act as the service coordinator?

How will service coordination benefit your to treatment of Lynn and your work with her family?

RESOLVE

Al and Lynn's doctor met to discuss her care and the family's situation. In addition to his general concerns about meeting Lynn's needs, her doctor was concerned that Lynn's father appeared tired and stressed.

Al and the doctor agreed that it would be helpful for the service providers to meet to discuss Lynn's services and, develop strategies for better coordinating and planning them. Al thought that the social worker from the children's hospital would be the best person to coordinate such a meeting. Together, Al and the doctor identified the appropriate medical information to send to the hospital social worker; the doctor sent a copy of these reports to Al as well. The doctor also wrote a cover letter with the reports and spoke with the social worker over the telephone, urging her to convene the meeting, and to discuss the details of planning it with Al. Although the doctor was unable to attend the service coordination meeting, he and Al did discuss the medical services which Lynn was going to need; they also discussed the reports which had been sent from other providers.

The service coordination meeting was held over lunch, so that Al did not have to miss any work time. The meeting's purpose was to address Al's concerns regarding Lynn's care and to establish an appropriate service coordinator. The following people were present:

Al
Al's sister, Janice
a representative from the home health care agency
the physical therapist from Easter Seals

the DMR case manager
Al's parent advocate
the social worker from the children's hospital
Lynn's daycare provider

Lynn's father began by listing his appointments over the last month. In a letter, Lynn's doctor commented that he felt that some of the problems of fragmented care could be addressed if as many appointments as possible were scheduled for the same day. Al had already contacted the social worker at the hospital to discuss scheduling. In addition, the team thought that many of the remaining scheduling issues could be handled by the nurse/case manager from the home health agency, who could coordinate all of Lynn's services with the various physicians. Lynn's doctor had told the hospital social worker that he would be available to consult on this matter.

The group then discussed Al's loss of certain insurance benefits. The parent advocate agreed to visit Al and Lynn one evening to review Al's eligibility for public funding for portions of the home health care, and to discuss options for therapy. The team agreed that, based on Al's income, he may be eligible for services through the State Health Department, and possibly eligible for Medicaid. The parent advocate will assist Al in understanding the process and in filing these applications. The group also agreed that the home health agency would clarify the existing insurance coverage for home health services.

Lynn's doctor had said that while he would not be able to attend meetings to coordinate care, he would consult with the service coordinator on the coordination of specialty services and continued planning of Lynn's medical needs. Although Al would like to take on the role of service coordinator, he may need assistance because of his work schedule. Al's sister agreed to assist him in this, she also said she would be more willing to assist in Lynn's care if someone could go with her to some of Lynn's appointments until she has a better understanding of Lynn's needs, and thus can be an effective advocate for her niece. Both the case manager from DMR and the parent advocate said they would be willing to assist in this process. The team agreed that Lynn's aunt's participation would aid in the transportation to appointments, but that scheduling still needed to be better coordinated. The team agreed to meet again in one month to review the service coordination plan. The home health agency agreed to host the meetings and to send out minutes to all the participants.

DISCUSSION - ANSWERS

As Lynn's primary pediatrician, evaluate the following:

What challenges do you see in coordinating services for Lynn?

- Services are provided by many agencies and health care providers
- The service providers are not functioning as a team and there is no appointed service coordinator
- There may be ways that more of the services could be provided "under the same roof," (i.e. within the school)
- Lynn's father, Al, is in a bind regarding his employment, the need to have continued insurance coverage, and the need to be available for Lynn's appointments
- Al's possible loss of essential services and funding sources
- The amount of time required for, and transportation to, all of Lynn's appointments
- Al appears to be extremely stressed despite his emotional support

What strengths does the family have which might assist it in coordinating services for Lynn?

- Al is clearly devoted to Lynn and wants to assure that all of her needs are met
- Al's sister provides emotional support and assistance with some of the daily routine
- Al is very knowledgeable about the resources available in the community

Who might act as the service coordinator?

- Al, with his sister's support, so it would not pose a threat to his employment
- One of the case managers from DMR, DHS, the nursing agency, or the children's hospital
- Al's sister with additional support
- A trained service coordinator as provided for in Part H of IDEA

How will service coordination benefit your ability to treat Lynn and work with her family?

- It will allow Lynn to receive effective, comprehensive treatment involving several disciplines
- I would gain knowledge of specific, non-medical goals and objectives for Lynn and her family
- Since service coordination includes identifying accessing, coordinating, and monitoring all services, Lynn and her family would be under less stress and receive more comprehensive care.

REFERENCES

Individuals with Disabilities Education Act (1991). P.L. 102-119 (20 U.S.C.) Sections 1400-1485.

Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Service Coordination Date

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
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I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

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TEAM PROCESS

Understand that successful interventions require all providers to function under a common philosophy with shared goals

Objectives:

Upon completion of this manual, you will be able to:

- **Distinguish between multidisciplinary, interdisciplinary, and transdisciplinary teams.**
- **Describe how the successful team process influences the life of a child with disabilities or special health care needs.**

A Child with disabilities may require the services of a wide variety of professionals (Bailey, 1989); those having medical, therapeutic, educational and developmental, and social service expertise may all be needed to 3 establish and implement a viable intervention program for an infant, young child, or adolescent. In addition to the individual needs of the infant or child, the emphasis and location of the program will further dictate professional staff needs. Whether such services are provided through an interagency or intra-agency team, the professionals involved will have to adopt a team model to ensure collaborative service delivery (McCollum & Hughes, 1988); they must be prepared to fully meet the self-identified needs of the family, as those needs relate to the child with disabilities. Their success will depend on the way the team functions.

The provisions of IDEA (Individuals with Disabilities Education Act for Children 3-21) and Part H of IDEA (for Infants and Toddlers, Birth to Three) require that both the assessment and the IFSP or IEP be completed by a multidisciplinary team consisting of the family and professionals from more than two disciplines. Such a group of individuals does not become a functional team merely by bestowing the label of "team" on it, however: rather, a group of people becomes a team when their purpose and function are derived from a common philosophy with shared goals (Maddux, 1988).

Models of Team Process

The types of teams that typically serve young children with disabilities have been identified as multidisciplinary, interdisciplinary, and transdisciplinary. On a **multidisciplinary team**, the professionals represent their own disciplines and provide their own assessments and interventions; these may include report writing, goal setting, and discipline-specific direct intervention for the child and/or the family. The parents are invited to share information with the professionals, while the professionals share the information from their assessment, intervention, and follow-up with the family through an "informing" conference. On a multidisciplinary team the family is a passive recipient of information about their child and professionals do little crossing of discipline lines, making it very difficult to develop and coordinate comprehensive programs for families and their children (McCormick, 1979).

On an **interdisciplinary team** each of the professionals carries out specific disciplinary assessments and interventions. The professionals and the family have a formal commitment to the sharing of information throughout the process of assessment, planning, and intervention (Bailey, 1984), and, usually, one team member is responsible for coordinating the child's services. The interdisciplinary team does some joint decisionmaking, but may have only minimal ongoing communication between team members and the parents.

By contrast, the members of a **transdisciplinary team,** share roles and systematically cross discipline boundaries (Hanson, 1989; McGonigal, 1988; Raver, 1991): this approach was originally conceived of as a framework within which professionals could share important information and skills with a child's primary caregivers. The transdisciplinary team develops a comprehensive intervention program in which a child's developmental needs are integrated across the major domains of communication, motor skills, and cognition (Hutchinson, 1978). The transdisciplinary team model also decreases the number of professionals from different disciplines with whom a child must deal on a daily basis (Rainforth, York & Macdonald, 1992). Further, in the transdisciplinary model all members of the team, especially the parents, participate in a continuous-give and-take on a regular, planned basis. Professionals from different disciplines teach, learn, and work together to accomplish a common set of service goals for a child and his or her family. The role differentiation among disciplines is defined by the needs of the situation, as opposed to the requirements of a specific discipline; designated members of the team jointly carry out assessments, interventions, and evaluations. The transdisciplinary model involves a greater degree of collaboration than other service models, however, and for this reason it may be difficult to implement.

In a transdisciplinary team model, the child's program is primarily implemented by a single person, or a few people. Team members from the various disciplines provide ongoing assistance by both direct service and by consultation. In most early intervention and special education programs, the teacher and program assistants take on the major direct-service role, but at times it is also appropriate for this role to be assumed by a special education teacher, who may provide services within the early childhood program on a regular basis. Support staff from related services most commonly therapists and health care workers, often serve as consultants. This does not mean that therapists stop providing direct services to the child; in order for therapists to be effective consultants, they need to maintain direct contact with the child. This team model should never be used as a strategy to justify reducing the support staff.

Although the transdisciplinary model may appear simple in concept, its implementation can be difficult. People tend to raise barriers to using a transdisciplinary team because of the differences between this and the more familiar, traditional teams. Such barriers may be philosophical, professional, interpersonal, or administrative (for a thorough discussion of these, see Orelove & Sobsey, 1991). In particular, the time commitment required to effectively implement a transdisciplinary team model across all disciplines may be prohibitive for early childhood programs. At a minimum, however, service delivery by more than one discipline requires a commitment to team process.

Effects of the Team Process

A functional team can overcome barriers, maintain the motivation to accomplish its mission and goals, and persevere to foster positive interactions among its members (Dyer, 1977; Starcervich, 1990). A number of variables contribute to effective team process, and are explained (Shonk, 1982) below.

Team Composition. The program or agency affiliation of the team members will exert a large influence on the team process. For example, the resources available to the team will depend on the participating staff, programs, or agencies. These resources can include not only skills and money, but administrative support and time. Teams with fewer resources will need to be more creative in identifying ways to achieve their goals.

Team Goals. Teams must devote time to identifying their goals and objectives. A truly effective team process can only exist when members share the responsibility for accomplishing common goals. An effective team will:

- **Set goals that are clearly understood and communicated to all team members.**

  A collaborative philosophy or mission is the team's overall reason for existence. It provides the team with a focus for its actions. A written statement of the collaborative philosophy will clearly delineate the transdisciplinary and interagency direction. A team will function effectively to the extent that its philosophy is clear and agreed upon.

- **Have ownership of the goals and participate in setting them.**

  All the team members (including the family) need to feel that their input is valued. This helps to ensure that the goals are supported by everyone on the team.

- **Set goals that are clearly defined and measurable.**

  Goals must be written in such a way that everyone has a clear understanding both of what is expected, and how successful mastery of these goals is to be determined and measured.

- **Share individual or personal objectives with one another.**

  Since teams are comprised of individuals, it is important to respect each member of the team.

Team Members and Roles. In order for teams to be effective, each individual must have a clear role and identified responsibilities: ambiguity is a great source of conflict. Team members must, therefore, continually clarify their roles.

In addition to the specific professional roles, responsibilities, and contributions of team members, members will have to assume other roles with regard to team development, leadership, maintenance, and problemsolving. These roles, or functions, must be established within the group in order for the team to work effectively.

To make their team process effective every team member has the responsibility to:

- Share expertise with other team members
- Offer recommendations for addressing a child's needs from their professional perspective or area of expertise
- Listen actively and communicate well. Be clear and concise when reporting information and avoid the use of jargon that other team members may not understand.
- Recognize the contributions of other team members, and encourage their sharing of information.
- Prepare the family for their role on the team and encourage their active participation.

Team Work Style. The team's work style will affect its development and overall effectiveness. In particular, the team will make effective decisions more consistently by using systematic problemsolving. If a team's problemsolving process is "haphazard, unconscious, or less than thorough" (Shonk, 1982), it is less likely to make decisions that will be optimum and appropriate. The team's problemsolving style will also affect how it implements its decisions. When a team applies a formalized, systematic problemsolving strategy, the probability of their achieving an effective outcome increases. Systematic problemsolving will ensure members are satisfied with, and committed to, the decisions they make.

Among the variety of problemsolving models that have been developed is PROJECT BRIDGE (Prentice & Spencer, 1986), a five-step decisionmaking model for teams. Each step in the problemsolving process should be used as a checkpoint for teams to evaluate their ideas and practices in terms of "best practices" for "exemplary services" in the field of early childhood special education. The steps outlined in PROJECT BRIDGE include:

- Problem Formulation and Information Gathering. The problem must be described in clear and observable terms. Resources should be identified, and the team should focus on the facts, rather than opinions.
- Generating Proposals for Solution. As many alternatives as possible should be generated from all participants. Without being judgmental, the team must build positively on all suggestions.
- Selecting Alternatives and Testing Solutions. The team must judge the available resources, and evaluate the alternatives for the solution. The team should decide whether or not the solution makes good use of the resources, is cost effective, and fits the needs and goals involved.
- Action Planning and Implementation. The team should assign specific responsibilities to individuals, determine timelines, and develop procedures for monitoring the plan. The plan is then communicated to all relevant professionals.
- Monitoring and Evaluation. The team should determine how to measure the success of their decision. The team should select a unit of evaluation, decide how often to evaluate, and plan to modify the plan as needed.

Problemsolving, as well as other team tasks, should occur during planned meetings. The team must work face-to-face in order to function its best. Thus, meetings are the hub of the team process. The team meeting can facilitate completing the team's tasks and achieving its goals. The well-functioning team meets at regularly scheduled times, with all team members attending. It is essential that all team members communicate regularly. An effective team meeting begins with a stated purpose or goal, as reflected in a written agenda. This agenda should be distributed before the meeting so that team members can prepare to discuss the issues that it describes. Structure and rules keep the meeting moving. These rules should establish participants' roles (including those of facilitator and recorder) and responsibilities, time frames for topics, and confidentiality policies. The minutes of the meeting record recommendations for action and for follow-up.

Team Leadership. A team is, of course, comprised of individuals who are products of their past experiences and have different attitudes, values, and beliefs about the world. These individuals also have expectations about the team, how it should function, and what it should accomplish. Because the personalities of the team members can ultimately determine the team's effectiveness, team leaders must adapt to meet team members' diverse needs and workstyles. The team leader must foster a climate in which all members feel free to contribute their ideas, express differing viewpoints, and offer solutions to problems.

Teams may have a formal leader who is assigned, appointed, or elected by the group, or an informal leader who may have emerged because of his or her influence, knowledge, skill, or personal qualities. The team may also informally accept someone as a leader because of ineffective formal leadership; often, both leaders operate simultaneously. Problems can occure if team members ignore these informal and formal roles, or misappropriate the functions of each. A team leader has a number of roles or functions with regard to a team's development, the main one being to focus the team on its responsibility to ensure the effective delivery, to the child with disabilities, of collaborative intervention services.

FAMILY STUDY

Polly is 18 months old and lives with her family in central Connecticut. She was born prematurely, and is the sole survivor of a set of triplets. Polly was hospitalized for 13 months following birth; her medical and developmental conditions include:

- Brain damage
- Heart problems
- Frequent infections that result in hospitalizations
- A dependency on oxygen
- Self-abusive episodes, including severe headbanging.

Because of her condition, Polly and her family have been receiving a variety of services since her return from the hospital. These include:

- Health care through her primary pediatrician
- Occupational therapy once per week
- Speech therapy once every other week
- Physical therapy once per week
- Home education through a Regional Education Service Center (RESC) twice per week
- Sixteen hours a day of home nursing care
- Medical supply vendors for special formulas and oxygen
- Specialty care at the hospital through a variety of clinics.

The family regularly has many professionals coming and going out of their house: during the five months that Polly has been home she has encountered five therapists, two teachers, ten nurses, and a hospital-based team comprised of a physician, two nurses, a psychologist, a full range of therapists, and a social worker. Also assigned to Polly's "case" are two social workers, three program supervisors, and three case managers from three separate agencies.

It is not surprising that Polly's parents are often caught in the middle of conflicts among the various professionals; each of whom seems to have a different opinion about Polly's needs, appropriate treatments, payment options, and service schedules. For example, each of the family's three case managers gave the family different information about their eligibility for various sources of public funding, including the Medicaid Waiver; as a result, their application for benefits was delayed and they had to pay several thousand dollars out-of-pocket for the cost of some of Polly's care. In addition, the nursing agency and the different therapists disagree about the amount of therapy Polly needs, and therefore do not cooperate with one another. Because there is no coordination among the service agencies and providers, the family finds that the services Polly receives often cause confusion in their lives. A week in their house looks like this:

- Monday: 16 (hours) nursing/teacher/supervisor/Department of Income Maintenance case manager
- Tuesday: 16 (hours) nursing/OT/DMR case manager
- Wednesday: 16 (hours) nursing/teacher/clinic visit at tertiary care hospital/PT
- Thursday: 16 (hours) nursing/PT/vendor delivery/nurse supervisor/teacher
- Friday: 16 (hours) nursing/speech therapy/adaptive equipment fitting at tertiary care hospital

- Saturday: 16 (hours) nursing
- Sunday: 16 (hours) nursing

The family has concluded that caring for Polly is **not** the primary cause of their stress, but rather that the multiple layers of fragmented services are causing much havoc in their family. Polly's parents are now seeking out-of-home placement for her because they feel that they need to put some order back into their lives. Neither parent feels "functional" with so many people in and out of their house. In Polly's case, one of the purposes of P.L. 99-457, reducing the likelihood of institutionalization, has not been realized.

DISCUSSION

As Polly's primary pediatrician, how would you use the concepts of team process to address this situation?

What are Polly's needs?

What are the family's concerns, priorities, and resources?

What are the service providers' concerns, priorities, and resources?

How can this group of people be shaped into a team? What would their goals be?

What type of team would best meet the needs of Polly and her family? Why?

What should the service team do to assist the family?

RESOLVE

The team which is providing services to Polly represents both interagency and intra-agency professionals. In order for them to provide transdisciplinary services, the members of the service team will have to collaboratively develop a service structure which accomplishes the IFSP goals, according to the family's schedule and priorities. One practice the service team must initiate is a regular time for meeting, during which they can identify mutual goals and service strategies. Since the nurses are the professionals in most frequent contact with Polly, it seems reasonable to the team to suggest that the nurses (along with Polly's parents) provide her with primary service delivery. In this scenario, the therapists and teachers will monitor Polly, but focus most of their effort on the training and support of the nurses and parents through consultation. The key to the success of this model will be the ability of the members to commit the time necessary to build relationships and release their roles for the benefit of Polly and her family.

DISCUSSION - ANSWERS

As Polly's primary pediatrician, how would you use the concepts of team process to address this situation?

What are Polly's needs?

- Occupational therapy, once a week
- Speech therapy, once every other week
- Physical therapy, once per week
- Nursing care, sixteen hours per day
- Oxygen

What are the family's concerns, priorities, and resources?

- Coordination of services among service agencies and providers
- Being caught in the middle of conflicts among professionals
- Health-care financing
- Too many people in and out of their home
- Out-of-home placement for Polly

What are the service providers' concerns, priorities, and resources?

- Appropriate treatments
- Service schedules
- Payment options

How can this group of people be shaped into a team? What would their goals be?

- They must meet together as a team to collaboratively develop a service structure which accomplishes the IFSP goals according to the family's schedule and priorities

What type of team would best meet the needs of Polly and her family? Why?

- A transdisciplinary team

- It would most effectively integrate services and communication across disciplines

- It would allow for equal input from all team members, especially Polly's family

What should the service team do to assist the family?

- The service team needs to work together to remove the stress Polly's family feels from the current lack of cooperation between providers. One way would be to use the consultation model to deliver services which would reduce the number of people in and out of their home.

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Early Intervention and Special Education in Connecticut

Training Manual Evaluation

Name of Manual Team Process Date ______________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

COLLABORATIVE CONSULTATION

Recognize that others are experts in their fields and that everyone can benefit from sharing information.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe how collaborative consultation benefits children with disabilities.**
- **Describe and apply the principles of successful collaborative consultation.**

Consultation is an important part of early intervention and special education services. Federal legislation (Individuals with Disabilities Education Act) recognizes that no one agency or service provider has all the knowledge and skills necessary to meet the diverse needs of children with disabilities and their families. Thus, professionals must coordinate and collaborate at the local, state, and federal levels (Trohanis, 1989). This coordination and collaboration require a commitment from service providers within agencies to jointly plan, implement, and evaluate programs. In order to do this, however, they will need to communicate with one another, share their expertise and skills, solve problems together and jointly make decisions that will result in exemplary service delivery to the child in need.

Models of Consultation

Many models for consultation have been used to provide services to children with disabilities (File & Kontos, 1992); generally speaking, consultation is the giving and taking of information between people for the purposes of:

- identifying and resolving a need, issue, or problem; and
- improving the consultee's understanding of, and ability to respond effectively to, similar problems in the future (Gutkin & Curtis, 1982)

Consultation, then involves at least two people who come together to resolve a need, issue or problem; one of these people may also be involved in different consultations with various staff members. What is most important, however, is the relationship between the two key individuals in the consultation. When the consultation concerns providing services to a child with a disability, the child becomes the third key person.

Consultation can be used to provide a child with a disability with two types of services: direct and indirect (Idol, 1993). The consultant's **direct services** may encompass the assessment of, and instruction in, a child's deficit area (Idol, Paolucci-Whitcomb, & Nevin, 1986). The consultant can also provide **indirect services,** such as assistance to teacher who has a child with disabilities in his or her classroom, as well as assistance to the parents of this child (Idol, 1993). Clearly, a child with disabilities will require both types of consultation.

Current research on consultation strategies has focused particularly on strategies used in problemsolving (Tindal, Shinn, & Rodden-Nord, 1990). Researchers have suggested that both people involved in a consultation (the consultant and the consultee) prefer a collaborative model (Babcock & Pryzwansky, 1983; Pryzwansky & White, 1983; Wenger, 1979) rather than an expert model. The **collaborative model** (derived from Tharp and Werzel, 1969) is "an interactive process which enables people with diverse expertise to generate creative solutions to mutually defined problems." The major outcome of collaborative consultation is to provide comprehensive and effective services within the most appropriate context to the child with special needs (Idol, et al., 1986, p. 1).

COMPETENCIES AND PRINCIPLES

Collaborative consultation requires many interpersonal competencies that cross disciplinary boundaries; among these competencies are written and oral communication skills; such personal qualities as the ability to be caring, respectful, empathic, congruent, and open; and collaborative problemsolving skills (West & Cannon, 1988). The last, in particular, is crucial to developing a relationship of parity between the consultant and the consultee.

A number of principles contribute to the success of collaborative consultation across professionals from different disciplines (Idol et al., 1986); including:

- **Mutual ownership of the process.**

  It is important that both consultant and consultee together identify the need, issue, and problem. They should both accept responsibility for, or ownership of, the consulting process and its subsequent outcome. It is important that both people respect, recognize, and appreciate each other's expertise.

- **Recognition of individual differences in the change process.**

  The consultant and consultee should both be aware of the change process and the developmental stages of concern for change (Hall & Loucks, 1978). It is important that both recognize that people embrace change differently, at different rates and at different emotional levels.

- **Use of reinforcement principles and practices to improve skills, knowledge and attitudes.**

  When both consultant and consultee use effective teaching skills with each other and the child with disabilities, everyone benefits.

- **Use of data-based decisionmaking.**

  Collaborative consultation requires adopting a model of evaluation to measure the functional outcome of the intervention for the child and/or the family. Both the consultee and the consultant must continuously assess their effect on the childs identified need or problem in order to evaluate the effectiveness of their collaboration.

Recent research has suggested that consultation is likely to become an increasingly prominent method of service delivery for the child with special health care needs and disabilities (File & Kontos, 1992), but one cannot advocate collaborative consultation for service delivery by professionals from different disciplines without concern. This concern is especially relevant when working with staff from different agencies who may have different philosophies of service, financial resources, and time constraints (Johnson & Pugach, 1991; Johnson, Pugach, & Hammitte, 1988). For example, staff from one agency or discipline may perceive themselves to be more highly skilled than those from another agency (Carter, 1989; Pugach & Johnson, 1989); this can happen in a collaboration between a physician and a special educator or related service provider, each of whom is skilled in his or her own area. It is important that the staff involved acknowledge any such existing barriers before beginning their collaboration. All staff members must demonstrate mutual respect, as each will benefit from the other's expertise. This is the very core of a collaborative consultation relationship.

FAMILY STUDY

Jeffrey is five years old and lives at home with his mother, father, and seven-year-old sister. Jeffrey was born prematurely at a tertiary care hospital, where he remained hospitalized for two months after birth. Among Jeffrey's medical and developmental concerns are:

- Respiratory problems during the first weeks of life
- Upon arrival home, he appeared not to be alert or active; his parents were concerned about his development
- He sat up at 8 months and walked at 15 months
- His visual-perceptual skills appear normal. He could put together simple puzzles and build intricate block towers at two.
- At two he had no verbal language and could not consistently follow a one-step direction. He showed no interest in playing with other children and barely acknowledged his parents and sister
- He would not allow anyone to hold him and engaged in ritualistic behaviors such as, rocking and playing with string. He became extremely upset and often tantrums if he was placed in a new situation or if people tried to share materials he was using

At age 2 1/2, Jeffrey's family pediatrician referred the family to the local early intervention program for an evaluation and a determination of his eligibility for early intervention services; the assessment and evaluation determined that Jeffrey was indeed, eligible for services. Jeffrey's family then worked collaboratively with the early intervention program to develop an educational plan to meet Jeffrey's needs. Both Jeffrey's family and the program were committed to inclusive education (learning in natural environments with typical peers). Jeffrey received special education and related services five mornings a week in the school district's preschool program. These services were provided by a special education teacher, a full-time aide to help in his educational program, speech and occupational therapists who came three times a week, and a psychologist who consulted with the team to develop behavioral strategies.

This team of professionals worked with Jeffrey for two years. During that time Jeffrey continued to have great trouble with transitions among different activities within the normal routines of the day. For example, when freeplay ended, Jeffrey had great difficulty putting away toys in preparation for storytime: he screamed, threw things, cried and ran about the room. Jeffrey seemed to trust both the adults and his peers in preschool, especially his preschool teacher, his aide, and a particular classmate. The team began to work collaboratively on some behavior modification techniques to be used both in school and at home, to help Jeffrey improve his abilities to make transitions, to communicate, and behave appropriately in social situations.

To assist Jeffrey in communicating, the speech therapist created a communication program, through which the therapist determined that Jeffrey, at age 4 1/2, could read and spell words. The speech therapist therefore suggested "facilitated communication" to the team. Facilitated communication assumes competence on the part of the child. The facilitator holds the child's hand (usually at the wrist to provide resistance) as the child points to letters on a board to spell out words. Families and professionals who use this method typically receive some brief training.

Jeffrey's speech therapist and his mother went for training and in turn trained the rest of the team.

Jeffrey is now five and the school district has agreed to place him in a regular kindergarten. In this school system, Jeffrey's educational team from preschool did not follow him to kindergarten. He started school instead with an entirely new team including the classroom teacher, a special education consultant, a speech therapist, an occupational therapist, psychologist, and a full-time aide.

Jeffrey seemed to lose many of the gains he had made in preschool. He began to have great trouble transitioning, both within the classroom and outside to different specials such as art, gym, and library: Jeffrey yelled, screamed and threw tantrums. His family requested that the team use some of the behavioral strategies developed for Jeffrey in preschool. The school psychologist, however, thought that Jeffrey was beyond behavioral strategies and recommended drug therapy to help Jeffrey control his behavior; the psychologist repeatedly alluded to Jeffrey as out of control and a danger to himself and other children, and the kindergarten teacher began to agree. The special education teacher suggested that the team work consistently on some behavioral interventions, and give them time. The family was devastated by Jeffrey's situation and the school psychologist's recommendation. They did not want their son on drugs because they had heard horror stories from other families; they also perceived that because everything was new in their son's life he would need time before he could begin to trust people again. The school principal decided to ask an outside consultant to help resolve this issue. You are the physician who is to meet with this team and address the issue of medication versus behavioral strategies.

DISCUSSION

As Jeffrey's physician, how will you facilitate this process?

How will you elicit information to determine the problem?

What are some of the factors that contributed to this problem?

How would you define the problem?

What are some of the possible solutions?

How will you facilitate collaborative decisionmaking in the group?

What is your intervention strategy?

How will you monitor this strategy?

What skills do you need to implement this collaborative consultation process?

RESOLVE

The physician agreed to consult with Jeffrey's team, which included the special education consultant, the full-time aide, the kindergarten teacher, his mother and father, the speech therapist, the school psychologist, the occupational therapist, and the school principal. Before the meeting, the physician arranged to observe Jeffrey during a kindergarten session: he saw Jeffrey exhibit many behaviors that interfered with his ability to learn and function in the classroom. The physician also saw the negative effect of these behaviors on Jeffrey's classmates, and the team's inconsistency in dealing with Jeffrey's poor behaviors during their scheduled therapy times in the classroom.

At the meeting, Jeffrey's physician asked the team to discuss the current problems. His goal, as consultant, was to help the team define the problem clearly and objectively, which requires gathering information about the problem and its circumstances. The physician listened a great deal and asked questions aimed at more clearly defining the problem, which had been called "out-of-control behavior." Everyone agreed that Jeffrey's behavior had been disrupting classroom routines, his learning, and the other students. Everyone also agreed that prior to kindergarten, Jeffrey's behavior had become very manageable through consistent behavioral intervention provided at the preschool. The physician's next step was to help the team diagnose, as accurately as possible, the causes for the problem. He asked them to think about why Jeffrey's behavior had become out-of-control, and helped the team to list some reasons for Jeffrey's drastic changes in behavior. The team decided the primary reason was the lack of transition planning and collaboration between the preschool team and the current school team; other reasons included Jeffrey's having to adjust to all the new staff, and the lack of consistency within the program or with intervention strategies. The speech therapist mentioned that Jeffrey had previously used facilitated communication, and that no one on the current team understood it. Once the group agreed on possible causes for Jeffrey's behavior, the physician moved on to the next step in the collaborative consultation process: helping the team formulate strategies that would allow Jeffrey and the team to more effectively manage his out-of-control behavior. The physician encouraged the group to brainstorm strategies based on their "diagnosis" list.

Once the team listed possible intervention strategies, the physician's role as consultant was to help them decide which intervention strategies to pursue. In this part of the consultation process the consultant sometimes uses constructive confrontation if team members put up barriers to the decisionmaking process. In this case, the school psychologist was adamant about drug therapy, and the physician was comfortable in confronting this view. He was able to explain that although drug therapy was indeed an option, it was one of the most restrictive and least desirable for both the child and his family.

The physician facilitated the team members to discuss the benefits for each strategy, identify resources needed to implement the different strategies, and explore the likelihood of success of specific strategies. Through a group decisionmaking process, the current school team decided to consult with the preschool team for technical assistance and information on the behavior modification strategies that had worked for Jeffrey. The team also concluded that they needed to help Jeffrey with his communication skills. Their plan for Jeffrey consisted of the principal allowing members of the team release time to meet with the preschool team; the speech therapist providing facilitated-communication training and implementing a program for the team; and the psychologist agreeing to develop a behavior modification plan relevant to Jeffrey's current environment and helping staff implement that plan consistently, based on information and technical assistance from the preschool team. Finally, the physician helped the team establish an evaluation plan, with timelines to implement these strategies: in particular, they would assess the behavior modification strategies over the next two months to determine Jeffrey's progress. While the physician agreed with some of the team members' that drug therapy is a solution for some behavior problems, he was firm in believing that other, less-aversive strategies should be tried and evaluated before drug therapy could be considered. The team agreed not only to meet with the physician in two months to look at outcomes Jeffrey's progress but to maintain ongoing contact as needed.

DISCUSSION - ANSWERS

As Jeffrey's physician, how will you facilitate this process?

How will you elicit information to determine the problem?

- Consult with the professionals who work with Jeffrey at his school
- Visit Jeffrey at his kindergarten session
- Consult with Jeffrey's parents about their needs and perspective

What are some of the factors that contributed to this problem?

- Jeffrey's trouble with transitions
- The inability of Jeffrey's school team to use facilitated communication
- Jeffrey's lack of trust of new adults and peers
- The school team's not using the behavioral strategies that had worked in his preschool program
- Lack of transition planning between the preschool team and the kindergarten team

How would you define the problem?

- Lack of transition planning between the preschool team and the current school team.
- All new people in his life
- Jeffrey has trouble communicating because no one in the new setting understands facilitated communication
- Disagreement about the use of drug treatment for Jeffrey's behavior
- Lack of respect for the parent's thoughts and feelings

What are some of the possible solutions?

- Collaboration with Jeffrey's preschool team
- Train the current school team in facilitated communication

How will you facilitate collaborative decisionmaking in the group?

- Have the group agree on the problem clearly and objectively by open discussion.

What is your intervention strategy?

- Have the current school team meet with the preschool team for technical assistance and information (especially on behavior modification)
- Have the current school team trained in facilitated communication

How will you monitor this strategy?

- Maintain ongoing communication with the team
- Have the team meet at a predetermined time (two months) to discuss progress

What skills do you need to implement this collaborative consultation process?

- The ability to listen
- The ability to use conflict resolution skills when there is disagreement
- The desire by all parties to arrive at the best solution for the child
- The ability to help the team generate creative solutions
- Effective communication skills

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Early Intervention and Special Education in Connecticut
Training Manual Evaluation

Name of Manual Collaborative Consultation Date ____________________

Please rate the following statements:	Strongly Disagree		Neutral		Strongly Agree
The layout and format of the manual were easy to use.	1	2	3	4	5
The manual was helpful in enabling me to understand the concepts introduced.	1	2	3	4	5
I feel that I learned from the manual.	1	2	3	4	5
The family study gave enough information to answer the discussion questions.	1	2	3	4	5
The discussion questions adequately tested my knowledge of the material.	1	2	3	4	5
The resolution adequately explained the key points of the family study.	1	2	3	4	5
I feel this manual would be an asset for the ICM-A class in learning more about children with special needs and my role in their educational systems.	1	2	3	4	5

Please add any comments about the above statements and/or any other comments you feel would help improve this manual for use in the ICM-A course.

Thank you for your assistance in evaluating this manual and filling out this evaluation form. Your comments and thoughts will help make this manual a success and in the process help tomorrow's physicians become more knowledgeable about their expanding role in the life of a child with special needs.

APPENDIX B

WORKING EFFECTIVELY WITH FAMILIES AND THEIR CHILDREN WITH DISABILITIES

PHYSICIANS TRAINING PROJECT
UNIVERSITY OF CONNECTICUT HEALTH CENTER
DEPARTMENT OF PEDIATRICS
DIVISION OF CHILD AND FAMILY STUDIES

Preface

The Division of Child and Family Studies, part of the University of Connecticut's Department of Pediatrics, administers numerous state and federal grants. These grants provide funding for research, demonstration, and training projects that offer service, support, resources, and materials to personnel from a variety of agencies and disciplines, as well as to families that have children with disabilities or special healthcare needs.

The mission of **The Division of Child and Family Studies** is to design, develop, and evaluate family-directed, comprehensive, collaborative, and community-based service delivery systems that will enhance the development of infants and children who have disabilities and/or chronic illnesses. In support of this mission, the Division of Child and Family Studies is administering a special projects grant, known as the Physicians Training Project. The purpose of this grant is to provide practicing pediatricians, pediatric residents, and medical students with information regarding their potential role in Connecticut's early intervention and special education systems.

This curriculum guide has been developed as a product of the Physicians Training Project. Its purpose is to enhance the clinical rotation experience of pediatric residents. The implementation of this curriculum utilizes three different modes of instructional delivery:

- Presentation and Discussion Sessions,
- Self-paced Training Manuals, and
- Practicum experience.

Each of these three modes of instruction has been designed to enhance the other modes of instruction. The presentation and discussion portions (Sections 1 and 2) of the curriculum will provide the resident with an opportunity to learn background information regarding early intervention, special education, and best practices. The self-paced training manuals (Sections 3, 4, and 5) will give the resident an opportunity to apply the theoretical model to case studies, seeing the importance of the application of best practices. Finally, the practicum experience (Sections 6 and 7) will give the resident the opportunity to discover the challenges and rewards associate with using best practices. Section 8 of this curriculum guide is a physician's reference to the services available in Connecticut for persons' with disabilities or special healthcare needs.

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3 FAMILY CENTERED CARE

4 EDUCATION LAW

5 TEAM PROCESS

6 HOME/PROGRAM VISITS

7 FORMS

8 PHYSICIAN'S REFERENCE

AVERY READY INDEX INDEXING SYSTEM

Contents

Introduction:	This section describes the purpose, goals, and design of the Physicians Training Project, as well as specific project components.
Training Sessions:	This section provides specifics about each of the three training sessions, including meeting time, presentation agenda, and the Resident's responsibilities.
Family Centered Care:	This self-study training manual includes the history of Family Centered Care, a family study, discussion questions, and a resolution.
Education Law:	This self-study training manual includes a description of major education laws, a family study, discussion questions, and a resolution.
Team Process:	This self-study training manual includes the key concepts of team process, a family study, discussion questions, and a resolution.
Home/Program Visits:	This section describes the purpose of each visist and contains an outline of suggested topics or questions to address.
Forms:	This section includes three required forms: the demographics/flow sheet, an authorization, and the project evaluation.
Physician's Reference:	This section contains a description of services available to children with disabilities and their families in Connecticut.

Introduction

Project Purpose

According to the Individuals with Disabilities Education Act, programs serving children with disabilities or special healthcare needs and their families must be family centered, comprehensive, community-based, and coordinated. To insure Connecticut's service delivery programs meet these standards, the **Division of Child and Family Studies** at the University of Connecticut Health Center's Department of Pediatrics is committed to developing, implementing, and evaluating training activities for healthcare professionals, and service providers for early intervention programs and other educational agencies.

One of the projects administered by the Division of Child and Family Studies is the **Physicians Training Project**. The goal of this project is to enhance the medical community's understanding of, and participation in the early intervention and special education systems in Connecticut. This project contains a variety of training experiences for medical students and pediatric residents, as well as practicing physicians.

As part of the Physicians Training Project, the Residency Training component expands the rotation experiences of Residents in the **Children with Special Health Care Needs Clinic (CSHCN)** at Newington Children's Hospital. This project involves the implementation of a training curriculum, a community-based visit in a school or childcare program, and a home visit with a family whose child has disabilities or special healthcare needs.

Project Design

This training curriculum includes project goals, component descriptions, training outlines, resident responsibilities, home and program visit guidelines, and various required forms. This curriculum also contains three self-study training manuals (Family Centered Care, Education Law, and Team Process) to augment the Resident's experience in the training sessions.

Each training manual is divided into four sections:

Background:	This section describes the concepts and values related to the topic.
Family Study:	This section describes a child with disabilities or special healthcare needs, including his or her medical and family histories.
Discussion Questions:	This section provides the Resident an opportunity to actively apply concepts described in the background to the family study.
Resolution:	This section provides a hypothetical solution to the family study, emphasizing the role and responsibilities the physician might have.

By adding this curriculum to the rotation, the Resident gains a broader understanding of the child and how his or her disabilities or healthcare needs affect life at home and in the community.

Project Contact People

Larry Kaplan, MD	Director, Children with Special Health Care Needs Clinic, Newington Children's Hospital, **667-5587**.
Molly Cole	Director, The Family Center, Newington Children's Hospital, **667-5288**.
Stephanie Goldstein	Training Associate, Division of Child and Family Studies, University of Connecticut Health Center, **679-4632**.

Project Goals

As a result of this project, residents will:

- *Enhance their understanding of the principles of Family Centered Care.*
- *Increase their awareness of the needs of a child with disabilities and special healthcare needs within his or her home environment and school or childcare program.*
- *Increase their appreciation for the strengths and needs of families, in relation to raising a child with disabilities or special healthcare needs.*
- *Gain knowledge of the key components of the Individuals with Disabilities Education Act (IDEA).*
- *Expand their understanding of team process and the role the physician should have within early intervention and special education programs.*

Project Components

The following project components have been designed to meet the goals of the Physicians Training Project. Each component is designed to stress the importance of family centered, comprehensive, community-based, and coordinated services for children with disabilities and special healthcare needs.

I. *Patient Selection Options*

❶ The Resident will identify a child who he or she is following in Continuity Clinic for the home and program visits. This is the **preferred** patient selection option.

or

❷ Dr. Kaplan will assign the Resident a child who is followed in CSHCN Clinic. In this case, caution will need to be taken to inform the child's parents the Resident will not provide on-going care. Rather, the Resident will provide a written statement of the family's and child's needs, concerns, and strengths. Dr. Kaplan will follow up with these families within his clinic.

or

❸ The Family Center will assign a family to the Resident. Again, caution will need to be taken to inform the child's parents the Resident will not provide on-going care. A written statement of the family's and child's needs, concerns, and strengths will be forwarded to The Family Center and, when appropriate, to the child's primary physician.

II. *Presentations*

On the first Friday of the rotation the Resident will attend a training session at The Family Center. The initial session will orient the Resident to the project and introduce the concept of family centered care. The Resident will attend additional training sessions on education law and team process, based on scheduling of the home and program visits. The last Friday of the rotation the Resident will discuss and evaluate their experiences.

III. *Visitations*

- **Home Visit:** The Resident will interview the family in their home to discuss their concerns, priorities, and resources related to living with a child with disabilities or special healthcare needs.

- **Program Visit:** The Resident will observe the child in his or her school or childcare program to determine how his or her needs are being met and, when possible, discuss with the teacher any concerns he or she may have about the child.

IV. *Materials*

- This curriculum guide, including three self-study training manuals on Family Centered Care, Education Law, and Team Process

- Presentation videos

- Additional handouts and program brochures

Training Session I

Day: First Friday of the month of rotation
Time: 10:00 a.m. - 12:00 p.m.
Location: The Family Center, Newington Children's Hospital

Presentation Agenda

- Overview of the Physicians Training Project
- The Family Center's history, philosophy, and projects
- Discussion of family centered care and family systems
- Video: Family Centered Care
- Discussion of the physician's role in a family centered model of care
- Discussion of the home visit and the program visit

Resident Responsibilities

- **Home Visit:** Once a family has been identified (see Patient Selection Options, Introduction, page 5), the Resident or a member of The Family Center will explain the project to the parents and, when appropriate, the child.

Continued...

The Resident will arrange the home visit **as early as possible** during the rotation month. The home visit should be set up at a time convenient to both the Resident and family. See next section for a comprehensive outline of the home visit.

- **Authorization:** The Resident or a member of The Family Center will obtain program contact information and a signed authorization for the Training Associate from UCONN to contact the school or childcare program (forms enclosed). This also should be done **as soon as possible** to allow time for contact with program personnel and arrangement of the program visit.

- **Readings:** Manuals on Family Centered Care and Education Law.

Training Session II

Day: Second or third Friday of the month
Time: 10:00 a.m. - 12:00 p.m.
Location: The Family Center, Newington Children's Hospital

Presentation Agenda

- Discussion of home visit, if completed
- Discussion of team process, the Individual Family Service Plan (IFSP), and the Individual Education Plan (IEP) process
- Video: Creating a New Vision: The IFSP or Teams in Action, and a clip from Heart to Heart
- Discussion of the role of the physician in the Individual Family Service Plan and Planning and Placement Team (PPT) process

Resident Responsibilities

- **Program Visit:** Once the authorization is obtained, the Training Associate from UCONN will contact the school or childcare program to set up the visit. During one of the Friday morning time slots, the Resident and Training Associate will attend the program visit together. Parents may join if they desire. See next section for a comprehensive outline of the program visit.
- **Readings:** Manual on Team Process.

Training Session III

Day: Last Friday of the month
Time: 10:00 a.m. - 12:00 p.m.
Location: The Family Center, Newington Children's Hospital

Presentation Agenda

- Discussion of home and program visits
- Discussion of education law, including the Individuals with Disabilities Education Act (IDEA)
- Wrap-up and final questions or concerns addressed

Resident Responsibilities

- **Discussion:** The Resident should come to this session prepared to discuss the following questions:
    - How are the concerns of the family and those of program personnel similar?
    - How are the concerns of the family and those of program personnel different?
    - Do the family and program personnel communicate about their respective concerns?
    - How are the concerns of the family and program personnel being addressed?

Continued...

  - In what ways could the physician provide support to the family in addressing their concerns?
  - What consultations or collaborations need to occur to address the needs of the family or child?
  - In what ways could the physician provide support to the child or program staff as it relates to the child's healthcare needs within the school or childcare setting?

- **Evaluation:** The Resident will complete evaluation form enclosed in curriculum binder.

- **Follow Up:** On the last page of the evaluation form the Resident **must** indicate any concerns raised by the family or program personnel that require further attention.

FAMILY CENTERED CARE

The family is the constant in every child's life.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe the Family Centered Care philosophy.**
- **Apply the nine principles of Family Centered Care.**

Philosophy

Family Centered Care is a philosophy developed by the former Surgeon General, C. Everett Koop, M.D., Sc.D. It is a philosophy of care which encompasses family centered, community based, coordinated services for children with special healthcare needs and their families. A major premise of this approach is that the child is part of a family, and that the family has great impact on the development and well-being of the child. A family centered approach to providing services to the child and his or her family thus depends on building and maintaining a relationship based on mutual trust and respect between professionals and the family.

The principles of family centered care were further defined and expanded upon in Family Centered Care for Children with Special Health Care Needs, published by the Association for the Care of Children's Health (ACCH) in 1987. In 1990, with input from a large group of families and providers of services to children with complex healthcare needs, ACCH revised and expanded the original number of principles to the nine which are currently accepted. The underlying premise of these nine principles is to develop systems of care that: 1) assist in the delivery of services to children with special healthcare needs, and 2) support the needs of the family (Shelton, Jeppson, and Johnson, 1987).

The family centered approach may represent a shift in orientation for some physicians and professionals in other fields. It is important that healthcare professionals become familiar with the family centered principles discussed below to ensure that the services being provided meet the needs of both the child and the family who is the center of care for that child.

The Nine Principles of Family Centered Care

1. **Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.**

   As a child grows and moves through the service delivery system, he or she will be involved with many professionals, specialists and agencies. The caregiving family will remain the consistent system for the child. It is essential that professionals recognize and respect this central role that the family plays in the care of their child. Ultimately, each family must assume responsibility for their child's care, both daily and for the long term. Professionals must learn to work in partnership with each family, valuing their judgment, and respecting their values and vision.

2. **Facilitation of parent/professional collaboration at all levels of healthcare.**

   Successful care plans must be developed through a meaningful collaboration that reflects each family's strengths and is tailored to each family's needs. The ultimate success of this process depends on the ability of parents and professionals to work together in partnership.

3. **Sharing of unbiased, complete information with the parents about the child's care on an on-going basis.**

   A true partnership between parents and professionals requires that parents have access to information which is communicated in an understandable way and in the family's primary language. This information includes: diagnosis and prognosis; available resources, including funding for services; and current research data.

4. **Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of the family.**

   Every family is unique. Each family's need for support will reflect their unique values, strengths, coping styles, and hopes for the future. Family support protocol suggests that families have access to "whatever it takes" to enable them to maintain their integrity and what they perceive to be their goals and visions. Their needs may include funding, respite, childcare, service coordination, parent-to-parent support, transportation, adaptive equipment, assistive technology, housing modifications, and advocacy.

5. **Recognition of family strengths and individuality with respect for different methods of coping.**

   Each family has its own strengths and sources of support: these may include neighbors, extended family, friends, and community associations. Professionals should work with the family to identify these support networks and develop strategies to strengthen and reinforce them. In addition, each family is defined differently and may include friends, as well as grandparents, brothers, sisters, aunts, and uncles. Services must be tailored to fit around this unique family system with its own specific goals, values, culture, and coping style.

6. **Understanding and incorporating the developmental needs of infants, children, and adolescents, and their families into healthcare systems.**

   In addition to each child's healthcare needs, a comprehensive healthcare plan must address other issues as well. Because each child and family has needs for socialization, development, and community support, the care plan should allow each parent to fulfill his or her role as parent, and each child to have as normal a life with family and friends as possible.

7. **Encouragement and facilitation of parent-to-parent support.**

Support from other families is valuable in developing successful coping strategies. Parent-to-parent support may involve matching experienced or "veteran" parents with a parent newly referred into the service delivery system. The veteran parents receive training in their roles as parent-to-parent support group volunteers, and each parent-to-parent support group is coordinated by a parent. Family supports can also include parent groups, led by professionals.

8. **Assurance that the design of healthcare delivery systems is flexible, accessible, and responsive to family needs.**

It is critical that service providers be able to respond to the ever-changing needs of each child and family with a flexible, accessible, and responsive system of services. Families often report that inflexible service systems and friction between parents and professionals are greater sources of stress than the daily care of their child. They report stresses such as rigid and conflicting eligibility criteria, confusing application forms, turf battles among agencies and service providers, and a fragmented, difficult-to-access system of services.

9. **Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.**

Each family has its own beliefs, values, strengths, and needs, and professionals need to guard against imposing their own values or cultural expectations upon the family. Care plans must enhance the family's strengths and address only those needs which the family itself has identified, rather than those which professionals believe exist.

Table 1 provides questions physicians should ask themselves to ensure they are providing family centered care:

Table 1

Topic	Questions
Family is Constant	• Have I identified the **family's** needs? • What can I do to help meet their needs? • Have I solicited the family's input? • Have I taken the family's needs into account when making my recommendations?
Collaboration	• Have I met with or contacted other professionals serving this family? • Have I let the family and professionals know how to contact me?
Information	• Have I been honest in providing the family with information about their child's condition? • Have I been supportive to the family, helping them to adjust to the needs of their child? • Have I presented all information in a clear and understandable way and in the family's primary language?
Policies and Programs	• Have I informed the family of agencies andservices that can help them deal with all issues related to the care of their child (for example, funding, education, service coordination, parent-to-parent support, transportation, adaptive equipment, housing modifications, and advocacy)?
Strengths and Individuality	• Have I helped the family identify its strengths? • Am I aware of the individual needs of this family?
Developmental Needs	• Does the treatment I prescribed allow the family and child to meet their normal needs?
Support	• Have I encouraged the family to seek out the support of other families and agencies?
Health Care	• Have I clearly informed the family of the services for which they qualify? • Have I collaborated with other professionals involved with this family to make sure the family is aware of all possible services that they qualify for? • Have I responded to the family's needs?
Values	• Have I considered the family's culture and values when prescribing my treatment?

FAMILY STUDY

JP is about to be discharged from the newborn intensive care nursery after a twenty-week hospitalization following his premature birth. He developed seizures at 72 hours, which were controlled by medication, and required ventilation for three weeks. He also had difficulty feeding by mouth. His mother, Susan, is a seventeen-year-old single parent in good health. She works an average of 30 - 40 hours a week, with no insurance benefits, as a secretary for a temporary employment agency. Susan must continue to work after JP comes home, and would like to find a permanent position with benefits. She worries about how she will pay for all of JP's needs.

Susan lives alone, and JP's father is not involved with the family. She has no family living nearby to assist her with JP's care; however, Susan does have a few close friends who have visited JP with her at the hospital. Susan will need support in making decisions about, and providing care for, JP.

When Susan was able to visit JP she often sat and rocked him for hours. Her missed visits made it difficult for the hospital staff to adequately train Susan in JP's care. However, toward the end of JP's hospitalization, Susan arranged for two days and one overnight at the hospital so she could learn JP's care plan and participate in the discharge planning process.

Susan lives in a one-bedroom apartment across town from the hospital. She does not have a telephone, so that maintaining contact with the hospital was difficult.

JP has a number of ongoing medical concerns, including the need for seizure medication and assistance during feedings. Because his muscle tone is poor, he is unable to suck for long periods. His calorie intake must therefore be monitored to make sure he gains enough weight.

Susan is committed to having him with her, but has a number of questions she would like answered before she takes JP home. The hospital social worker questions Susan's abilities to adequately care for JP. As the community pediatrician who will be caring for JP, you are responsible for making sure the transition to home goes smoothly.

DISCUSSION

As JP's primary pediatrician, apply the nine principles of Family Centered Care to identify the following:

What are the family's strengths and resources?

What are the family's needs/concerns?

Who should explore the issues affecting Susan's ability to visit JP in the hospital and to participate in his care? How should these issues be addressed? What is the family's role in discharge planning?

What are the potential barriers to implementing the discharge plan?

Who addresses the barriers identified in the discharge meeting?

What are the providers' (professionals) issues?

What do you want included in the discharge plan for JP?

DISCUSSION - ANSWERS

As JP's primary pediatrician, apply the nine principles of Family Centered Care to identify the following:

What are the family's strengths and resources?

- Susan loves JP
- Susan's strong determination to provide care for JP at home
- Susan took time off from work to participate in the planning process for JP's discharge
- Susan visited JP despite transportation difficulty
- Susan has some friends for emotional support
- Susan has kept her job throughout the stress and trauma of JP's hospitalization

What are the family's needs/concerns?

- Insurance Benefits
- Child care
- Transportation
- Help coordinating JP's doctors' appointments
- Support for Susan to help her understand JP's needs
- Employment counseling for Susan
- Telephone

Who should explore the issues affecting Susan's ability to visit JP in the hospital and to participate in his care? How should these issues be addressed? What is the family's role in discharge planning?

- Susan, JP's pediatrician, primary care nurse, discharge planner (nursing), and social worker should be involved in identifying the issues affecting Susan's ability to visit JP in the hospital and participate in his care.
- These issues should be addressed in a team meeting of the above individuals in a collaborative, family centered manner; they should all work toward the goal of JP being cared for at home with his mother.
- The family's role should be as an equal team member in the discharge planning.

What are the potential barriers to implementing the discharge plan?

- Susan's need for a telephone
- Health care financing
- Transportation
- Susan's ability to get JP to multiple appointments without losing her job
- Susan's support needs
- Child care

Who addresses the barriers identified in the discharge meeting?

- The entire discharge-planning team should address these issues.

What are the providers' (professionals) issues?

- Making sure JP has his medical needs met at home, including medical equipment, medicine, therapy and appropriate medical and early intervention referrals.

What do you want included in the discharge plan for JP?

- Medical equipment from a home health supply vendor
- Medication for seizures
- Referral to early intervention and physical therapy
- Referrals for medical follow-up appointments

RESOLUTION

Susan was committed to caring for JP at home. Despite limitations in transportation, she did manage to visit JP and was very nurturing towards him, spending hours in the hospital rocking and hugging him. Prior to his discharge, she learned how to care for JP, including how to operate all of his medical equipment. Susan had a few friends who provided her with emotional support. She had managed to keep her job despite the stress and trauma of JP's hospitalization, and was struggling to meet both of their needs.

Using a family centered model, the following people began discharge planning for JP after the sixth week of his hospitalization, when his health stabilized:

Susan
Primary NICU Physician
Primary Nurse
Discharge Planner (Nursing)
Social Worker (Hospital Based)
Visiting Nurse (Community Based)
Community Pediatrician

The discharge planning included three team meetings: at 8 weeks, 16 weeks, and just prior to discharge. Susan was able to attend only one of these meetings, but met with JP's primary nurse before and after each meeting to discuss the plans and her own concerns. Susan also met with the hospital social worker on four other occasions. The visiting nurse made one visit to Susan's home before discharge and assessed JP's home care needs.

During the discharge planning process, Susan identified several of her concerns, including a lack of insurance benefits, She would need to find child care for JP, and expected that this would be difficult because of his medical and developmental needs. She did not have a car of her own and worried about being able to return for medical appointments with JP. She was also concerned about taking too much time off from work. She also had questions about JP's long-term care needs and prognosis. She felt that she had no one to support her and assist her in understanding these issues.

With Susan's input relayed by the primary nurse, the team wrote the discharge plan at their last meeting. Afterwards, the nurse met with Susan to explain the plan. A referral for early intervention was discussed with Susan and she said she would think about it. Her copy of their discharge summary included telephone numbers and appointments, and information on the following medical needs:

- The medical equipment needed and the home-health supply vendor phone number
- Proper dosages and administration of medications for seizures
- Referral to early intervention services for developmental follow-up and physical therapy

- Referrals for follow-up in the following specialties: ophthalmology, neurology, pulmonology, audiology, and developmental follow-up clinic

- Referral for eight hours of home nursing per day

In addition to JP's medical/developmental needs, Susan's other concerns were addressed through the discharge plan.

- **Susan's need for a telephone.** The hospital social worker secured a donation from a local charitable foundation to have a phone installed; Susan understood that ongoing bills would be her responsibility.

- **Health care financing.** Susan was assisted in applying for Medicaid (Title XIX) and WIC (Food supplement for pregnant women, infants and children). At the time of JP's discharge, she had met the eligibility requirements: JP's care, as well as her own, was covered.

- **Transportation.** Medicaid would pay for transportation to medical appointments.

- **Multiple care providers and appointments.** The visiting nurse agreed to act as a service coordinator, and would assist Susan in coordinating appointments on the same day.

- **Support needs for Susan.** Prior to JP's discharge, Susan was offered support through Parent-to-Parent, a network of trained "veteran" parents who have children with disabilities. She was matched up with another mother, who visited her several times at the hospital, and they planned to continue meeting after discharge. The discharge plan also contained a referral to an employment counseling agency which would help Susan find permanent work.

- **Child care needs for JP.** JP would receive eight hours a day of home nursing while Susan was working; this coverage would continue as long as JP needed skilled care. Should his condition improve, Susan would again need to find child care. The Visiting Nurse Association would assist her in training a childcare provider, but Susan was aware that this care may be costly and difficult to secure.

With the appropriate support, including a good relationship with JP's primary care pediatrician, Susan and JP can eliminate barriers to implementing a successful discharge plan and effectively deal with the challenges they face in the future.

RESOURCES

Brewer, E.J., Magrab, P.R., & Hutchins, V.L. (1989). Family-centered, community-based, coordinated care for children with special health care needs. Pediatrics, 83, 1055-1060.

Brown, W., Thurman, S.K., & Pearl, L.F. (1993). Family-centered early intervention with infants and toddlers: Innovative cross-disciplinary approaches. Baltimore: Paul H. Brookes.

Koop, C.E. (1987). Surgeon General's Report: Children with Special Health Care Needs - Campaign '87 - Commitment to Family-Centered, Coordinated Care for Children with Special Health Care Needs. Washington, DC: US Department of Health and Human Services.

Shelton, T., Jeppson, E., & Johnson, B. (1987). Family-centered care for children with special health care needs (2nd ed.). Washington, DC: The Association for the Care of Children's Health.

EDUCATION LAW

The Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) address many facets of the child's educational and healthcare needs.

Objectives:

Upon completion of this manual, you will be able to:

- **Describe the Individuals with Disabilities Education Act (IDEA) and apply concepts of the law to children with disabilities.**
- **Describe Part H of IDEA (early intervention) and list the services available for eligible infants and toddlers.**
- **Describe the Americans with Disabilities Act (ADA) and apply concepts of the law to children with disabilities.**

As the primary physician treating a child with disabilities, it is important to become familiar with the laws affecting the education of this child. These education laws have many components and specific provisions which are described below.

Chronology of Special Education Law

1973 - Section 504, The Rehabilitation Act

Key Components: Mandates that services be provided to persons with a wide array of disabling conditions including training for and placement in full-time, part-time, or supported employment in the competitive labor market.

1975 - The Education for All Handicapped Children Act (P.L.94-142)

Key Components: Part B requires states to: furnish all children with disabilities (ages 3-21) a free, appropriate public education in the least restrictive environment; the provision of special education and related services designed to meet the unique needs of these children; and the development of an Individualized Educational Plan for each child.

1986 - Amendments to The Education for All Handicapped Children Act (P.L. 99-457)

Key components: The addition of Part H provides for: the development of "a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers (birth to three years of age) with disabilities and their families"; the establishment of a State Interagency Coordinating Council; and the development of an Individualized Family Service Plan for each eligible infant or toddler and his or her family.

1990 - The Americans with Disabilities Act (ADA)

Key Components: A wide-ranging civil rights law that prohibits discrimination against people with disabilities or physical and mental impairments that substantially limit their activities such as working, walking, talking, seeing, hearing, or caring for themselves; the requirement that employers make reasonable accommodations for employees with disabilities; and prohibition of discrimination in commercial facilities and in any activity or service operated or funded by state or local government, including daycare centers and other programs which serve children without disabilities.

1991 - Individuals with Disabilities Education Act (P.L. 101-476, IDEA)

Key Components: This reflects a name change which shifts the terminology from "handicaps" to "disabilities" and encompasses all of the components from The Education for All Handicapped Children Act and its amendments.

Individuals With Disabilities Act (IDEA)

Special education is defined as "specially designed instruction, delivered at no cost to the parent, to address the unique needs of the child" in accordance with an **Individualized Education Plan (IEP).** The child may receive this instruction in the classroom, in the home, in hospitals and in other settings, such as community early childhood programs.

Under **Part A General Provisions**, this law stipulates that:

- The eligible disabilities include mental retardation, hearing impairments, speech and language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, and specific learning disabilities.

- **Related services** (see Appendix A) be provided, including:

  Transportation and such developmental, corrective, and other supportive services as may be required to assist a child with a disability to benefit from special education: these include speech therapy, audiology, psychological services, physical and occupational therapy, recreation (including therapeutic recreation), early identification and assessment of disabilities in children, counseling services (including rehabilitative counseling), and medical services for diagnostic or evaluative purposes. The term also includes school health services, social work services in schools, and parent counseling and training.

- Transition services be provided for secondary-age students.

Major Components Of IDEA

- **The Zero Reject Principle:** A free, appropriate public education is guaranteed for all children ages 3-21 regardless of the severity of the individual's disability. Children under three may be provided with services if state law, regulation, or judicial ruling mandate them.

- **Nondiscriminatory Assessment**: A multidisciplinary team must conduct the evaluation in the child's primary language or mode of communication, using observations and non-biased, validated instruments. The student must be assessed in all areas related to the suspected disability. The assessment should allow the child to display his or her abilities and strengths, as well as disabilities.

- **Individualized Education Plan (IEP)**: An appropriate Individualized Education Plan must be written for each child. This document should be developed in a Planning and Placement Team (PPT) meeting composed of parents, a school administration representative, the child's teacher, members of the evaluation team, and others (such as a physician) invited by the parents or the school. The IEP will contain a statement of the child's current level of performance, long term goals and short term objectives, specific educational services the child will need, the date for beginning services and the anticipated duration of the services, the extent of the child's participation in the regular education program, and how to determine whether the goals and objectives for the child are being met.

- **Least Restrictive Environment (LRE):** To the maximum extent possible, schools must educate children who have disabilities with their peers who do not have disabilities:

  a) Special classes, separate schooling, or otherwise removing a student with disabilities from regular education should occur only when the nature or severity of the disability is such that education in regular classes cannot be achieved satisfactorily even with the use of supplementary aids and services.

  b) Schools must provide a spectrum of placement options (regular classes, regular classes with minimal support, regular classes with one-to-one assistance, special education classes, etc.), and supplementary services (adaptive physical education, speech and language, etc.).

  c) Schools must provide education as close to the student's home as possible, and allow a student to participate in extracurricular and nonacademic activities to the extent appropriate.

  d) If a child with disabilities, is removed from a regular education classroom, the school must work to return that child to the regular classroom as soon as possible.

- **Due Process and Parent Participation**: School districts must establish and follow specific procedures in order to protect the rights of children and their families. These procedures should specify that:

  a) Parents may examine all records pertaining to their child.

  b) Parents have the right to obtain an independent evaluation of their child, in addition to that provided by the school district and its staff.

c) Parents must be given the opportunity to consent or object to the identification, evaluation, or placement of their child. They must be informed of the Planning and Placement Team (PPT) conference and encouraged to participate. Meetings must be scheduled at times convenient for parents and appropriate communications must be maintained with them.

d) Parents or guardians must receive written notice if a change is proposed in their child's classification, evaluation, or educational placement.

e) Parents have a right to an impartial due process hearing conducted by a hearing officer, and/or mediation if they are in disagreement with the school district. Parents have the right to be represented by a lawyer, to give evidence, and to cross-examine. Hearings may be requested by the parent or by the school district.

f) Surrogate parents must be appointed to provide representation and informed consent for children whose parents or guardians are not known, or who are not available.

In addition to the above provisions these amendments include an emphasis on meeting the needs of traditionally under-represented populations (for example, minorities or low-income families). The amendments also expand the definition of special education to include a variety of settings for the delivery of services (for example, a work place or community-based program). States must also insure that **assistive technology devices** and/or **assistive technology services** are made available to a child with a disability if they are required as a part of the child's program. Thus, a child's program may include special education, related services, and/or supplementary aids and services. The legislation states, further, that the related services list is not exhaustive and may include other developmental, corrective, or supportive services, if they are required to assist a child with a disability to benefit from education.

Part H of IDEA, Early Intervention Services for Infants and Toddlers, also provides incentives for states to develop an early intervention entitlement program which is based on a comprehensive, interagency, and multidisciplinary model of service delivery. The following key components are required under Part H:

- **Lead Agency:** Each state is to designate a lead agency which will be responsible for the administration of funds under Part H. In Connecticut the lead agency is the State Department of Education.

- **State Interagency Coordinating Council:** Each state is required to establish a State Interagency Coordinating Council whose role is to advise and assist the lead agency for early intervention. The membership of the state **ICC** will include at least:

  a) three parents of infants or toddlers with disabilities

  b) one representative from the state legislature

  c) three public or private providers of early intervention services

  d) one person involved in professional preparation

  e) other representatives from each of the appropriate agencies involved in the provision of or payment for early intervention services

  f) others appointed by the Governor

- **Point of Entry:** A comprehensive child find system is to be established as the point of entry into the early intervention system. Such will include procedures that ensure that all eligible infants and toddlers are identified, located, and evaluated. In Connecticut the point of entry is through the six Regional Family Service Coordination Centers across the state.

- **Individualized Family Service Plan (IFSP):** Each eligible infant or toddler and his or her family shall receive a multidisciplinary assessment and an Individualized Family Service Plan (IFSP) which should include:

  a) the present level of the child's development

  b) a statement of the family's priorities, resources, and concerns

  c) a statement of expected major outcomes for the child, which may include social behavior, adjustment to the family, as well as developmental goals

  d) a statement of necessary services for the child

  e) projected dates of these services, and their duration

  f) the steps for supporting the child's transition from the early intervention program to the mandated special education program within the local school district at age three

  g) the name of a service coordinator

- **Service Coordination:** The appointment of a service coordinator who is responsible for assisting and enabling an eligible child and his or her family to receive the rights, procedural safeguards, and services which are to be provided under the early intervention program. Service coordinators serve as the single point of contact for the family and all service providers. Service coordination is provided at no cost to the parents.

- **Payment:** As Part H does not come under a free, appropriate education, the lead agency will establish "policies related to how services to children eligible under this part and their families will be paid for." In addition, "the inability of the parents of an eligible child to pay for services will not result in the denial of services to the child or the child's family." (Section 303.520).

FAMILY STUDY

Trevor is a nine year old boy who lives with his mother, Sandy, and his father, John. Trevor has two sisters; Lisa, who is six years old, and Ann, who is four. Sandy delivered Trevor 12 weeks prematurely by emergency Cesarean Section. Trevor's birth weight was low, and he was hospitalized for four months because of repeated respiratory distress. Sandy and John visited their son regularly in the hospital and were involved in his hospital care.

Trevor was discharged from the hospital with respiratory problems and required frequent feedings and medications. His parents cared for him at home with little support. Trevor has developmental delays, as documented by a multidisciplinary evaluation requested by his parents shortly after he came home from the hospital at six months of age. Trevor began receiving early intervention services at fifteen months of age. The concerns were as follows:

- Trevor has cerebral palsy; he is, however, ambulatory.
- He has a very narrow airway or breathing passage.
- He has vision difficulties, wears prescriptive lenses, and requires preferential seating in school.
- Trevor has repeated bouts of respiratory infections for which he often receives antibiotics.
- Trevor has learning disabilities.
- He has attention problems which require medication.

Presently, Trevor is in a "self-contained" classroom (for students with learning disabilities) at the fourth grade level, which is appropriate for his age. This is the first year that Trevor has been in the self-contained classroom. The Planning and Placement Team (Trevor's parents and appropriate school personnel) decided that this was the most appropriate program for him. This decision was based on the following concerns:

1. Trevor often required that instructions about assignments be repeated.

2. Trevor's behavior in the mainstream or "regular ed" (for non-disabled peers) classroom was often disruptive, and the teacher had a difficult time getting him and the rest of the class back on task.

3. Class sizes were increasing, and the teacher would not be able to give Trevor the more "individualized" instruction he might need.

4. The school staff judged that Trevor's learning disability and his physical disability dictated a more "restrictive" educational setting.

Trevor's Individual Education Plan (IEP) was developed by the Planning and Placement Team and he was placed in the self-contained classroom. After an initial period in this special education environment, Trevor's parents had reasons to reconsider this placement. Trevor's behavior had worsened since he had been in the self-contained program and his pediatrician was concerned that he was acting out his anger and unhappiness about being in this class. Additionally, Trevor was attending a different school than other children in the neighborhood, including his sister Lisa. This made child care arrangements even more difficult for his parents to manage. Trevor's parents requested an additional Planning and Placement Team meeting to revise his Individual Education plan and to include the following:

- Placing Trevor in a regular education setting with modifications to the curriculum and/or school day in order to assist him in learning

- The provision of appropriate special education and related service supports

- Completion of a comprehensive evaluation to assess Trevor's current functioning levels and educational needs

- Encouraging Trevor to have appropriate interactions with his peers with the goal of establishing positive relationships

For the Planning and Placement Team meeting the neurologist sent a letter supporting Trevor's placement in a regular education setting with modifications and support services. His parents brought an advocate, a distant cousin of his mother's who was a special education teacher. The

Planning and Placement Team meeting lasted three hours. However, the participants could not reach an agreement about the most appropriate program for Trevor. To resolve this dispute, Trevor's parents filed the required forms with the Department of Education to begin due process.

DISCUSSION

As Trevor's primary physician, answer the following:

According to the Individuals With Disabilities Education Act (IDEA) and Americans With Disabilities Act (ADA), what should be your role in addressing Trevor's educational needs?

Based on the information presented regarding Trevor's educational needs, does the Individuals with Disabilities Education Act afford Trevor the opportunity to participate in a regular education program?

If, according to the IDEA, Trevor should participate in a regular education program, what part or parts of the IDEA specifically address Trevor's educational needs?

What are the parental and family issues? How has the family appropriately asserted their right to have those issues taken into consideration when Trevor's IEP is developed?

If Trevor were two years old, how might this process be different under IDEA Part H?

DISCUSSION - ANSWERS

As Trevor's primary physician, evaluate the following:

According to the Individuals With Disabilities Education Act (IDEA) and Americans With Disabilities Act (ADA), what should be your role in addressing Trevor's educational needs?

- Collaborate with members of the PPT and other healthcare providers regarding Trevor's medical needs and the impact of these needs on his educational programming
- Clearly state Trevor's needs for medical intervention within the school, such as dispensing of medications
- Ascertain whether a comprehensive evaluation of Trevor's educational and related service needs has been completed
- Determine the need for any assistive technology services or devices

Based on the information presented regarding Trevor's educational needs, does the Individuals with Disabilities Education Act afford Trevor the opportunity to participate in a regular education program?

- Yes

If, according to the IDEA, Trevor should participate in a regular education program, so, what part or parts of the IDEA specifically address Trevor's educational needs?

- Development of an IEP defining eligibility needs for special education programming and related services (Part A)
- Part B (for ages 3-21)
- Least Restrictive Environment

What are the parental and family issues? How has the family appropriately asserted their right to have those issues taken into consideration when Trevor's IEP is developed?

- Parents feel that the self contained classroom is not benefiting Trevor because:
    - a) It is not in the neighborhood school
    - b) It excludes Trevor from the mainstream or regular classroom
    - c) They see Trevor's behavioral difficulties increasing
    - d) It complicates their child care arrangements
- Less restrictive alternatives within the neighborhood school or the regular education classroom were not tried prior to placing Trevor in the self contained program
- Trevor may be in need of a comprehensive evaluation, including a medical evaluation
- His parents do not feel supported by the school staff
- Trevor needs to have contact with non-disabled peers
- Parents appropriately requested a PPT meeting to review Trevor's program and sought support from their pediatrician, their neurologist, and an advocate

If Trevor were two years old, how might this process be different under IDEA Part H?

- Under Part H an IFSP would be written rather than an IEP, and would include a statement of the family's strengths and needs, the name of a service coordinator, and possibly steps for moving Trevor into the public schools at age three

RESOLUTION

Trevor's parents filed for a due process hearing with the local school district. As the law states, the State Department of Education must schedule the hearing and render a decision within 45 days of the initial request for the hearing. Sandy and John thought that up to this point they had a working relationship with Trevor's school team; after discussing the issue, they decided to ask the school district officials if they would instead be interested in mediation as an intermediate step in the process. The law (P. L. 101-476) does allow for mediation, which is defined as an informal process for resolving disagreements about a student's special education evaluation, program, or placement. In order to obtain mediation, both the parent or guardian and the school district must send written requests to the State Board of Education. The School District agreed to try mediation; the State Board of Education then scheduled a date and appointed a state mediator to help work out a solution acceptable to both parties. The family understood that if mediation did not work, their initial request for a due process hearing would still be valid.

Trevor's parents decided to ask his neurologist, who prescribes and monitors Trevor's medication, to attend the mediation session; they also asked Trevor's primary pediatrician to attend. Both physicians agreed to come because they thought it was important to establish along with school personnel, a mechanism for ongoing communication about and evaluation of Trevor's progress. Both physicians strongly believed that Trevor should be placed back in regular fourth grade in his neighborhood school, with the classmates he had been with since first grade. The neurologist believed that knowing more about a typical day in regular fourth grade, and the expectations for Trevor within that day, might influence his prescription and timing of Trevor's medication. The neurologist also thought it was important for Trevor to have a behavior management plan in conjunction with his medication.

The pediatrician believed he had good rapport with Trevor and his family, and a sense of how Trevor reacted to certain stresses and conditions. He noted that Trevor wanted to express that he felt different and angry at being placed in the self-contained fourth grade class, instead of a regular fourth grade with his friends. The pediatrician thus recommended that Trevor speak on his own behalf at mediation, and said that he would help facilitate the process for Trevor. He also said he would be willing to work with Trevor, the school psychologist, Trevor's family, and other team members to develop a behavior management plan that was consistent for home and school. Trevor's parents agreed that these were important issues to raise at mediation, and thought that both physicians not only supported their concerns but wanted to work collaboratively with school district personnel. His parents further agreed that it was important to let Trevor speak at the meeting and for school district officials to hear his concerns.

Trevor's parents also asked Trevor's third-grade teacher to attend the mediation. She had told Trevor's parents during the PPT that she would have recommended regular fourth grade if appropriate support services could be worked out. She believed Trevor did not have ongoing, consistent supports in third grade, thus making it difficult for her to manage his inclusion in that class. The family wanted to stress to the school staff that when Trevor had previously been placed in regular education, he did not have supplementary supports, a curriculum plan, and a behavior management plan.

The family asked the advocate to attend as well. Trevor's parents were comfortable with the team of professionals they had chosen to go with them to mediation. They believed that the group would support their goal of an inclusive fourth grade placement for Trevor, and offer ongoing support to school personnel if they agreed to place Trevor back in regular education. The family went to mediation with a positive attitude. However, if mediation did not work, they were prepared to pursue this issue at a due process hearing, which is their right under the law.

Since their last PPT meeting, the advocate had told Trevor's parents of a ruling in U.S. District Court for the district of New Jersey; she said she would bring copies of the summary of the opinion for everyone at the mediation. In brief, the court defined inclusion as follows:

> "When a child with a disability is placed as a full member of a regular class with the provision of supplementary aids and services this is known as supported inclusive education."

The court also noted that:

> "An inclusive education program, where a child with a disability becomes a member of a regular class, does not imply that all special service delivery must occur within the regular class. For instance, resource room support, or other special services, may be delivered on a pull-out basis within the regular class, or a combination of the two, depending upon the needs of the child and the class as determined by the teachers and team involved."

The court ruled that any Individual Education Plan that recommends self-contained special education classes with no meaningful opportunities for integrating the child with non-disabled children violated IDEA. The school district also violated IDEA when it placed the student in a regular class for a portion of the day without supplementary support, a curriculum plan, or a behavior management plan. Trevor's parents felt that their concerns were supported: this is exactly what they had been trying to explain to school district officials in terms of Trevor's initial placement in regular education.

RESOURCES

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APPENDIX A

Types of services available for eligible infants and toddlers under Part H of IDEA (P.L. 101-476, Sections 303.12, 303.13, and 303.22):

Assistive technology device: any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of children with disabilities.

Assistive technology service: a service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device.

Audiology: identification of children with auditory impairment, referral for medical and other services necessary, provision of auditory training, and determination of the child's need for individual amplification.

Family training, counseling and home visits: services provided, by social workers, psychologists, and other qualified personnel to assist the family of a child in understanding the special needs of the child and enhancing the child's development.

Health services: services necessary to enable a child to benefit from the other early intervention services, including such services as clean intermittent catheterization, tracheostomy care, tube feeding, the changing of dressings or colostomy collection bags, and other health services; consultation by physicians with other service providers concerning the special healthcare needs of children that will need to be addressed in the course of providing other early intervention services.

Medical services only for diagnostic or evaluation purposes: services provided by a licensed physician to determine a child's developmental status and need for early intervention services.

Nursing services: the assessment of health status for the purpose of providing nursing care; provision of nursing care to prevent health problems, restore or improve functioning, and promote optimal health and development; administration of medications, treatments, and regimens prescribed by a licensed physician.

Nutrition services: conducting individual assessments; developing and monitoring appropriate plans to address the nutritional needs of children; making referrals to appropriate community resources to carry out nutrition goals.

Occupational therapy: services to address the functional needs of a child related to adaptive development, adaptive behavior and play, and sensory, motor, and postural development designed to improve the child's functional ability to perform tasks in home, school, and community settings.

Physical therapy: services to address the promotion of sensorimotor function through the enhancement of musculoskeletal status, neurobehavioral organization, perceptual and motor development, cardiopulmonary status, and effective environmental adaptation.

Psychological services: administering psychological and developmental tests and other assessment procedures; interpreting assessment results; obtaining, integrating, and interpreting information about child behavior, and child and family conditions related to learning, mental health, and development; planning and managing a program of psychological services.

Service coordination services: coordinating all services across agency lines; serving as the single point of contact; assisting parents in gaining access to the early intervention services and other services identified in the Individualized Family Service Plan; coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided.

Social work services: evaluating a child's living conditions and patterns of parent-child interaction; preparing a social or emotional developmental assessment of the child within the family context; providing counseling with parents, other family members, and with the child and parents; identifying, mobilizing, and coordinating community resources and services to enable the child and family to receive maximum benefit from early intervention services.

Special instructional services: the design of learning environments and activities that promote the child's acquisition of skills in a variety of developmental areas, including cognitive processes and social interaction; curriculum planning, that leads to achieving the outcomes in the child's Individualized Family Service Plan; providing families with information, skills, and support related to enhancing the skill development of the child; working with the child to enhance the child's development.

Speech/language pathology: identification of children with communicative or oropharyngeal disorders and delays in development of communication skills; referral for medical or other professional services; provision of services.

Transportation and related costs: the cost of travel (e.g., mileage, or travel by taxi, common carrier, or other means) and other costs (e.g., tolls and parking expenses) that are necessary to enable a child and the child's family to receive early intervention services.

Vision services: evaluation and assessment of visual functioning, including the diagnosis and appraisal of specific visual disorders, delays, and abilities; referral for medical or other professional services; communication skills training, orientation and mobility training for all environments, visual training, and additional training necessary to activate visual motor abilities.

TEAM PROCESS

Understand that successful intervention requires all service providers to function under a common philosophy with shared goals.

Objectives:

Upon completion of this manual, you will be able to:

- **Distinguish between multidisciplinary, interdisciplinary, and transdisciplinary teams.**
- **Describe how the successful team process influences the life of a child with disabilities or special health care needs.**

Children with disabilities may require the services of a wide variety of professionals. Those having medical, therapeutic, educational, developmental, and social service expertise may all be needed to establish and implement a viable intervention program for an infant, young child, or adolescent. In addition to the individual needs of the infant or child, the emphasis and location of the program will further dictate professional staff needs. Whether such services are provided by an interagency or intra-agency team, the professionals involved will need to adopt a team model which ensures collaborative service delivery. They must be prepared to fully meet the self-identified needs of the family, as those needs relate to their child with disabilities. The success of service delivery will depend on the way the team functions.

The provisions of IDEA (Individuals with Disabilities Education Act for Children 3-21) and Part H of IDEA (for Infants and Toddlers, birth to three) require that both the assessment of the child and the development of the Individual Family Service Plan or Individual Education Plan be completed by a team consisting of the family and professionals from more than two disciplines. Such a group of individuals does not become an effectively functioning team merely by calling themselves a "team". Rather, a group of people becomes a team when their purpose and function are derived from a common philosophy with shared goals.

Models of Team Process

The types of teams that typically serve young children with disabilities have been identified as multidisciplinary, interdisciplinary, and transdisciplinary. On a **multidisciplinary team**, the professionals represent their own disciplines and provide their own assessments and interventions. Responsibilities may include report writing, goal setting, and discipline-specific direct intervention for the child and/or the family. The parents are invited to share information with the professionals, while the professionals share information from their assessment, intervention, and follow-up with the family through an "informing" conference. On a multidisciplinary team the family is a passive recipient of information about their child and the professionals do little crossing of discipline-specific lines. This makes it very difficult to develop and coordinate comprehensive programs for families and their children.

On an **interdisciplinary team** each of the professionals also conducts discipline-specific assessments and interventions. The professionals and the family have a formal commitment to the sharing of information throughout the process of assessment, planning, and intervention (Bailey, 1984). Usually, one team member is responsible for coordinating the child's services, but the interdisciplinary team does some joint decision-making.

By contrast, the members of a **transdisciplinary team** share roles and systematically cross discipline boundaries (Hanson & Lynch, 1989).

This approach was originally conceived of as a framework within which professionals could share important information and skills with a child's primary caregivers. The transdisciplinary team develops a comprehensive intervention program in which a child's developmental needs are integrated across the major domains of communication, motor skills, and cognition (Hutchinson, 1978). The transdisciplinary team model also decreases the number of professionals from different disciplines with whom a child must deal on a daily basis (Rainforth, York & Macdonald, 1992). Further, in the transdisciplinary model all members of the team, especially the parents, participate in a continuous give-and-take on a regular, planned basis. Professionals from different disciplines teach, learn, and work together to accomplish a common set of service goals for a child and his or her family. The role differentiation among disciplines is defined by the needs of the situation, as opposed to the requirements of a specific discipline; designated members of the team jointly carry out assessments, interventions, and evaluations. The transdisciplinary model involves a greater degree of collaboration than other service models, and for this reason it may be more difficult to implement.

In a transdisciplinary team model, the child's program is primarily implemented by a single person, or a few people. Team members from the various disciplines provide ongoing assistance by both direct service and consultation. In most early intervention and educational programs, the teacher and program assistants take on the major direct service responsibilities. At times it is also appropriate for this role to be assumed by a special education teacher, who may provide services within the classroom on a regular basis. Support staff from related services, most commonly therapists and healthcare workers, often serve as consultants. This does not mean that therapists stop providing direct services to the child, since they need to maintain some direct contact with the child in order to be effective consultants. It is cautioned that this team model not be used as a strategy to justify reducing the support staff.

Implementation of the transdisciplinary model can be difficult because of the differences between this and more familiar, traditional models of team process. Individuals may raise barriers to the interdisciplinary team model based on philosophical, professional, interpersonal, or administrative differences. In particular, the time commitment required to effectively implement a transdisciplinary team model across all disciplines may be prohibitive. At a minimum, however, service delivery by more than one discipline requires a commitment to team process.

Effective Team Process

A functional team can overcome barriers, maintain the motivation to accomplish its mission and goals, and persevere to foster positive interactions among its members. The following section explains the number of variables that contribute to an effective team process.

Team Composition: The program or agency affiliation of the team members will exert a large influence on the team process. For example, the resources available to the team will depend on the participating staff, programs, or agencies. These resources can include not only skills and money, but administrative support and time. Teams with fewer resources need to be more creative in identifying ways to achieve their goals.

Team Goals: Teams must devote time to identifying their goals and objectives. A truly effective team process can only exist when members share the responsibility for accomplishing common goals. An effective team will:

- **Set goals that are clearly understood and communicated to all team members.**

  A collaborative philosophy or mission is the team's overall reason for existence. It provides the team with a focus for its actions. A written statement of the collaborative philosophy will clearly delineate the transdisciplinary and interagency direction. A team will function effectively to the extent that its philosophy is clear and agreed upon.

- **Have ownership of the goals and participate in setting them.**

  All the team members (including the family) need to feel that their input is valued. This helps to ensure that the goals are supported by everyone on the team.

- **Set goals that are clearly defined and measurable.**

  Goals must be written in such a way that everyone has a clear understanding both of what is expected, and how successful mastery of these goals is to be determined and measured.

- **Share individual or personal objectives with one another.**

  Since teams are comprised of individuals, it is important to respect each member of the team.

Team Members and Roles: In order for teams to be effective, each individual must have a clear role and identified responsibilities: ambiguity is a great source of conflict. Team members must, therefore, continually clarify their roles.

In addition to the specific professional roles, responsibilities, and contributions of each individual on the team, members will need to assume other roles with regard to team development, leadership, maintenance, and problem-solving. These roles, or functions, must be established within the group in order for the team to work effectively. To make the team process effective every team member has the responsibility to:

- Share information and expertise with other team members.
- Offer recommendations for addressing a child's needs from their professional perspective or area of expertise.
- Listen actively and communicate well. Be clear and concise when reporting information and avoid the use of jargon that other team members may not understand.
- Recognize the contributions of other team members, and encourage their sharing of information.
- Prepare the family for their role on the team and encourage their active participation.

Team Work Style: The team's work style will affect its development and overall effectiveness. In particular, the team will make effective decisions more consistently by using systematic problem-solving. If a team's problem-solving process is "haphazard, unconscious, or less than thorough" (Shonk, 1982), the team is less likely to make decisions that are optimum and appropriate. The team's problem-solving style will also affect how it implements its decisions. When a team applies a formalized, systematic problem-solving strategy, the probability of achieving an effective outcome increases. Systematic problem-solving will ensure that members are satisfied with, and committed to, the decisions they make.

A variety of problem-solving models have been developed. Among them is PROJECT BRIDGE (Prentice & Spencer, 1986), a five-step decision-making model for teams. Each step in the problem-solving process should be used as a checkpoint for teams to evaluate their ideas and decisions, particularly in terms of "best practices" or "exemplary services" in the field of early childhood special education. The steps outlined in PROJECT BRIDGE include:

- **Problem Formulation and Information Gathering.** The problem must be described in clear and observable terms. Resources should be identified, and the team should focus on the facts, rather than opinions.
- **Generating Proposals for Solution.** As many alternatives as possible should be generated from all participants. Without being judgmental, the team must build positively on all suggestions.
- **Selecting Alternatives and Testing Solutions.** The team must judge the available resources, and evaluate alternatives for the solution. The team should decide whether or not the solution makes good use of the resources, is cost effective, and fits the needs and goals involved.
- **Action Planning and Implementation.** The team should assign specific responsibilities to individuals, determine timelines, and develop procedures for monitoring the plan. The plan is then communicated to all relevant professionals.
- **Monitoring and Evaluation.** The team should determine how to measure the success of their decision. The team should select a unit of evaluation, decide how often to evaluate, and modify the plan as needed.

Meetings are the hub of the team process. The team must work face-to-face in order to function at its best. Problem-solving, as well as other team tasks, should occur during planned meetings. The well-functioning team meets at regularly scheduled times, with all team members attending. It is also essential that all team members communicate regularly. An effective team meeting begins with a stated purpose or goal, as reflected in a written agenda. This agenda should be distributed before the meeting so that team members can prepare to discuss the issues that it describes. Structure and rules keep the meeting moving. These rules should establish participants' roles (including those of facilitator and recorder) and responsibilities, time frames for topics, and confidentiality policies. The written minutes of the meeting document the discussion and recommendations for action and follow-up.

Team Leadership: A team is comprised of individuals who are products of their past experiences and who have different attitudes, values, and beliefs about the world. These individuals also have expectations about the team, how it should function, and what it should accomplish. Because the personalities of team members can ultimately determine the team's effectiveness, team leaders must be able to adapt to meet team members' diverse needs and work styles. The team leader must foster a climate in which all members feel free to contribute their ideas, express differing viewpoints, and offer solutions to problems.

Teams may have a formal leader who is assigned, appointed, or elected by the group, or an informal leader who may have emerged because of his or her influence, knowledge, skill, or personal qualities. The team may also place someone in an informal leadership position because the formal leadership is ineffective. Often, both leaders operate simultaneously. Problems can occur if team members ignore these informal and formal roles, or misappropriate the functions of each. A team leader has a number of roles or functions with regard to a team's development, the main one being to focus the team on its responsibility to ensure the effective delivery of collaborative intervention services to children with disabilities and their families.

FAMILY STUDY

Polly is 18 months old and lives with her family in central Connecticut. She was born prematurely, and is the sole survivor of a set of triplets. Polly was hospitalized for 13 months following birth. Her medical and developmental conditions include:

- Brain damage
- Heart problems
- Frequent infections that result in hospitalizations
- Dependency on oxygen
- Self-abusive episodes, including severe head banging

Because of her condition, Polly and her family have been receiving a variety of services, including:

- Health care through her primary pediatrician
- Occupational therapy once per week
- Speech therapy once every other week
- Physical therapy once per week
- Home education through a Regional Education Service Center (RESC) twice per week
- Sixteen hours a day of home nursing care
- Medical supply vendors delivering special formulas and oxygen
- Specialty care at the hospital through a variety of clinics

The family regularly has many professionals coming to and going from their house. During the five months that Polly has been home services have been provided by five therapists, two teachers, ten nurses, and a hospital-based team comprised of a physician, two nurses, a psychologist, a full range of therapists, and a social worker. Also assigned to Polly's care are two social workers, three program supervisors, and three case managers from three separate agencies.

It is not surprising that Polly's parents are often caught in the middle of conflicts among the various professionals; each of whom seems to have a different opinion about Polly's needs, appropriate treatments, payment options, and service schedules. For example, each of the three case managers gave the family different information about their eligibility for various sources of public funding, including the Medicaid Waiver. As a result, their application for benefits was delayed and they had to pay several thousand dollars out-of-pocket for some of Polly's care. In addition, the nursing agency and the different therapists disagree about the amount of therapy Polly needs, and therefore do not cooperate with one another. Because there is no coordination among the service agencies and providers, the family finds that the services Polly receives often cause confusion in their lives. A week in their house looks like this:

- Monday: 16 hours nursing/teacher/supervisor/Department of Income Maintenance case manager
- Tuesday: 16 hours nursing/OT/DMR case manager
- Wednesday: 16 hours nursing/teacher/ clinic visit at tertiary care hospital/PT
- Thursday: 16 hours nursing/PT/vendor delivery/nurse supervisor/ teacher
- Friday: 16 hours nursing/speech therapy/adaptive equipment fitting at tertiary care hospital
- Saturday: 16 hours nursing
- Sunday: 16 hours nursing

The family has concluded that caring for Polly is not the primary cause of their stress, rather that the multiple layers of fragmented services are causing much havoc in their family. Polly's parents are now seeking out-of-home placement for her because they feel the need to put some order back into their lives. Neither parent feels "functional" with so many people in and out of the house. In Polly's case, one of the intents of P.L. 99-457, reducing the likelihood of institutionalization, has not been realized.

DISCUSSION

As Polly's primary pediatrician, how would you use the concepts of team process to address this situation?

What are Polly's needs?

What are the family's concerns, priorities, and resources?

What are the service providers' concerns, priorities, and resources?

How can this group of people be shaped into a team? What would their goals be?

What type of team would best meet the needs of Polly and her family? Why?

What should the service team do to assist the family?

DISCUSSION - ANSWERS

As Polly's primary pediatrician, how would you use the concepts of team process to address this situation?

What are Polly's needs?

- Occupational therapy, once a week
- Speech therapy, once every other week
- Physical therapy, once per week
- Nursing care, sixteen hours per day
- Oxygen

What are the family's concerns, priorities, and resources?

- Coordination of services among service agencies and providers
- Being caught in the middle of conflicts among professionals
- Health-care financing
- Too many people in and out of their home
- Out-of-home placement for Polly

What are the service providers' concerns, priorities, and resources?

- Appropriate treatments
- Service schedules
- Payment options

How can this group of people be shaped into a team? What would their goals be?

- They must meet together as a team to collaboratively develop a service structure which accomplishes the IFSP goals according to the family's schedule and priorities

What type of team would best meet the needs of Polly and her family? Why?

- A transdisciplinary team
- It would most effectively integrate services and communication across disciplines
- It would allow for equal input from all team members, especially Polly's family

What should the service team do to assist the family?

- The service team needs to work together to remove the stress Polly's family feels from the current lack of cooperation between providers. One way would be to use the consultation model to deliver services which would reduce the number of people in and out of their home.

RESOLUTION

The team which is providing services to Polly represents both interagency and intra-agency professionals. In order for them to provide transdisciplinary services, the members of the service team will have to collaboratively develop a service structure which accomplishes the Individual Family Service Plan goals, according to the family's schedule and priorities. One practice the service team must initiate is a regular time for meeting, during which they can identify mutual goals and service strategies. Since the nurses have the most frequent contact with Polly, it seems reasonable to the team to suggest that the nurses (along with Polly's parents) provide her with primary service delivery. In this scenario, the therapists and teachers will monitor Polly, but focus most of their effort on the training and support of the nurses and parents through consultation. The key to the success of this model will be the ability of the members to commit the time necessary to build relationships and release their roles for the benefit of Polly and her family.

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The Home Visit

Purpose

- To gain an increased understanding of the child within his or her home environment, and the family's strengths and needs as they realte to their child's disability or special healthcare needs.

Family Interview - Suggested Outline

- Identify the **positive** experiences the family has had in their home, community, school or childcare program(s), and the healthcare system.
  - *What factors have contributed to making these experiences positive?*
- Identify difficulties the family has had in their home, community, school or childcare program(s), and in the healthcare system.
  - *What factors have contributed to these difficulties?*
  - *How might these issues be addressed?*
  - *What role could the physician play in addressing these issues?*
- Identify the family's current concerns and needs with regard to the home environment, school or childcare program(s), and healthcare system.
  - *What supports might be offered to this family?*

Continued...

- Discuss the components of the child's current school or childcare program:
  - *Is the child receiving early intervention or special education services?*
  - *Is the child included in a class or setting with children who do not have disabilities, a mainstream or inclusive environment?*
  - *Does the child receive related services such as occupational therapy, physical therapy, speech and language therapy, and counseling? Where are these services provided?*
  - *Does the child use any assistive technology at school, such as a computer, an assistive language device, a modified spoon, or velcro on a writing tool?*
  - *How do the child's healthcare needs impact his or her ability to participate in the program?*

Please obtain the following information:

Name of Parents ______________________________

Name of Child ____________________ Age ________

Child's School/Childcare ________________________

Address of Program ____________________________

Contact Person ______________ Phone ____________

Obtain a signed authorization (form enclosed) to contact childcare/school personnel.

Date of signed release __________

Please phone Stephanie with the above information and return the original signed release to her at UConn as soon as possible.

The Program Visit

Purpose

- To gain an enhanced understanding of the school or childcare program, particularly as it relates to the child's disabilities or special healthcare needs.

- To consider what role the physician or other healthcare providers should play in addressing the child's health concerns within the school or childcare program.

Program Observation - Suggested Outline

- Identify the components of the child's program:

    - *What is the setting?*

    - *What is the teacher-to-student ratio?*

    - *What kind of program is it: a regular or specialized childcare; a mainstream public school classroom; or a special education program?*

- Identify the individualized services being provided to the child:

    - *Is he or she receiving specialized instruction?*

    - *Are any ancillary therapies being provided (e.g., physical or occupational therapy, speech and language therapy, or counseling)?*

    - *Are any assistive devices being used (e.g., a wheelchair, computer, modified seating)?*

Continued...

- Identify how the child's disabilities or special healthcare needs impact his or his ability to participate within this program:
    - *Is the child included in all classroom activities?*
    - *What accommodations need to be made to include the child in certain activities?*
    - *Are there any activities in which the child is not included?*
- Identify the **positive** elements of the school/childcare program as you observe them:
    - *What appears to be going well for the child?*
    - *Is there interaction between the child and the other students?*
- Discuss with the teacher any of his or her concerns pertaining to this child:
    - *Does the teacher identify any need for support regarding the child's healthcare needs?*
- Identify the child's service delivery team:
    - *Does the team include a physician?*
    - *Does the team appear to be well coordinated?*
    - *Is there an appointed service coordinator or case manager?*

Physicians Training Project
Demographics/Flow Sheet

Resident Information

Name ______________________________

Phone Number ______________________________

Beeper Number ______________________________

Month of Rotation ______________________________

Have you had any experience with children
with disabilities and their families? ☐ **Yes** ☐
No

If yes, when and in what context? (Please explain) ______________

____

Patient Information

Child's Name ______________________________

Parents Names ______________________________

Address ______________________________

Phone Number ______________________________

Name of Program ______________________________

Contact Person/Title ______________________________

Program Phone Number ______________________________

Continued...

Visitation Information

Purpose of program explained to parent ______________________

By whom ____

Date of home visit _______________________________________

Names of those present at home visit _______________________

Release to contact school obtained _________________________
______

Date program contacted __________________________________

By whom ____

Date of first program visit ________________________________

Date of second program visit ______________________________
______

Presentation Dates

Family Centered Care ____________________________________

Team Process ____

Educational Law ____

Notes

Newington Children's Hospital
181 East Cedar Street
Newington, CT 06111
667-KIDS

____
Child's Name Birth Date

The above named child and the child's family are participating in the Physicians Training Project through Newington Children's Hospital and UConn Health Center. The family has given us authorization to contact the Local Education Agency regarding this child, as follows:

The Newington Children's Hospital is hereby authorized to contact my child's school, ____________________ and the Board of Education in the city/town of ______________ to discuss my child's educational program with appropriate staff, and to visit the school to observe my child's educational program.

The purpose of this contact is to provide information and observations that will assist in training pediatric residents through the Physician' s Training Project at Newington Children's Hospital and the University of Connecticut Health Center in Farmington, CT.

______________________________ __________
Parent/Legal guardian signature Date

______________________________ __________
Witness Date

Any information shall remain confidential, and shall not be transmitted to anyone else without written consent or other authorization as provided in the Connecticut General Statutes.

This authorization may be revoked by me at any time, except to the extent that action has been taken in reliance thereon. This authorization, unless expressly revoked earlier, expires in one year from the date signed.

Physicians Training Project

Division of Child and Family Studies, UConn Health Center

Evaluation of Residency Component

Name: ____________________________ Date: _________________

Please rate the following statements on a scale of 1 through 5 by circling your chosen response:

- **1** indicates that you **strongly disagree** with the statement
- **2** indicates that you **somewhat disagree** with the statement
- **3** indicates that you are **neutral** about the statement
- **4** indicates that you **somewhat agree** with the statement
- **5** indicates that you **strongly agree** with the statement

		Strongly Disagree		**Neutral**		**Strongly Agree**
A.	*CONTENT*					
1.	Objectives of the training were met.	1	2	3	4	5
2.	All topics on the agenda were addressed.	1	2	3	4	5
3.	Time was well organized.	1	2	3	4	5
4.	The **information** gained is relevant and can be applied to my work situation.	1	2	3	4	5
5.	This **experience** will enhance the way I deliver services to patients and their families.	1	2	3	4	5
6.	I have a better understanding of the role a physician might have in a child's educational program.	1	2	3	4	5
7.	The concepts of Family Centered Care and Team Process are applicable to my work setting.	1	2	3	4	5
8.	I am more aware of education law as it pertains to children with disabilities and special healthcare needs.	1	2	3	4	5

B. *PRESENTATIONS*

	Strongly Disagree		Neutral		Strongly Agree
1. The presenters were well prepared and organized.	1	2	3	4	5
2. The presenters communicated in a clear and understandable manner.	1	2	3	4	5
3. The presenters valued my input.	1	2	3	4	5
4. The presenters addressed my questions and concerns.					
5. The materials (e.g., handouts, videos, manuals) were relevant to the training.	1	2	3	4	5

C. *HOME VISIT*

1. My patient was from:
__ Continuity Clinic
__ Children with Special Health Care Needs Clinic
__ The Family Center
__ Other: ________________________________

	Strongly Disagree		Neutral		Strongly Agree
2. The home visit was easy to arrange.	1	2	3	4	5
3. I found the parents to be open and available for discussions about their child.	1	2	3	4	5
4. I gained information about the child's needs in the home.	1	2	3	4	5
5. I gained a sense of the **positive** aspects of this child's life from the family's perspective.	1	2	3	4	5
6. I gained a sense of the parent's concerns regarding their child.	1	2	3	4	5
7. I discovered ways in which a physician might be helpful to the family and child.	1	2	3	4	5

D. *PROGRAM VISIT*

		Strongly Disagree		Neutral		Strongly Agree
1.	I gained information about the child's needs in the school/ childcare setting.	1	2	3	4	5
2.	I gained a sense of the **positive** aspects of this child's life from the teacher's perspective.	1	2	3	4	5
3.	I gained a sense of the teacher's concerns regarding this child's special needs.	1	2	3	4	5
4.	I discovered ways in which a physician may be helpful to the child and the staff at the school or childcare program.	1	2	3	4	5

E. *OVERALL*

1. What did you find most helpful about this experience?

2. Did you have any difficulties during this experience? If so, please describe them fully.

3. What additional information or opportunities would you like to see included in this training?

4. What might you do differently in your practice as a result of this training?

5. In your own words please complete this phrase: This experience provided me...

6. **Important:** Please list those needs identified by the family or program staff that require further attention:

As soon as possible, please return this form to:

Stephanie Goldstein
Training Associate
University of Connecticut
Division of Child and Family Studies
Farm Hollow, A200
309 Farmington Avenue
Farmington, CT 06032

Thank you very much for your participation in the Physicians Training Project and your honest feedback.

PHYSICIAN'S REFERENCE

Services for Children with Disabilities and Their Families

Introduction

A wealth of government programs and services exists that can provide support to your young patients with disabilities and their families. You, the physician, often has the opportunity and the responsibility to link families with the appropriate programs and services. **But what exactly are these programs, what do they offer, and how do you find them?**

To aid you in your search, we have outlined in this section **who does what, who is eligible,** and **who to call.** The alphabetical table of contents can guide you to the appropriate pages. **INFOLINE** (p. 27) can also help you find the resources you seek. A cross-referenced index listing types of services and where they can be found is included at the end of this section.

Where you see "*Additional information available," you will find a separate page in this section containing further details about that specific agency or program. Please note that calling one program within an agency will not always link families with other programs in the same agency.

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Aid to Families with Dependent Children (AFDC)

What is AFDC?

Aid to Families with Dependent Children (AFDC), a program run by the Department of Social Services*, offers financial assistance to low income families so they can provide such basic necessities as food, clothing, and shelter to their dependent children. People receiving support through **AFDC** are automatically eligible for Medicaid* (Title XIX), which pays for medical expenses.

Who is Eligible?

The Department of Social Services determines **AFDC** eligibility on the basis of family size, income level, and assets. (If assistance is denied, appeals may be directed to the Fair Hearing Division of the Department of Social Services). **AFDC**, in general, serves:

- single-parent families or two-parent families in which one of the parents is disabled, unemployed, or employed less than 100 hours per month
- eligible children, even if no eligible adult resides with them
- pregnant women in their third trimester who do not have other minor children

What does AFDC Provide?

- A monthly benefit for basic living expenses: rent, food, clothing, utilities, and household supplies

*Additional information available.

- Participation in a training and employment program
- Child Support Enforcement Services
- Access to other benefits which may also be available: energy assistance, food stamps, child care assistance, emergency housing, transportation to hospitals or medical appointments

Where do you Request Information and Applications?

Department of Social Services: Offices are open Monday through Friday, 8:30 a.m. - 4:30 p.m. Spanish-speaking staff are available.

Bridgeport	579-6850	New Britain	827-7160
Bristol	583-1671	New Haven	789-7555
Danbury	797-4034	Norwalk	838-2373
Hartford	566-5900	Norwich	823-5000
Manchester	647-1441	Stamford	357-8144
Meriden	238-6200	Torrington	482-5531
Middletown	344-2121	Waterbury	596-4152

Birth to Three Services
Part H of the Individuals with Disabilities Education Act (IDEA)

What are Birth to Three Services?

Early intervention services are provided to infants and toddlers (from birth to three years old) with developmental disabilities or chronic illnesses and their families as mandated in Part H of the Individuals with Disabilities Education Act (P.L. 101-476).

Birth to Three programs provide assistance to families to identify and coordinate the screening, evaluation, and early intervention services that their infants and toddlers need. Services are designed to meet the needs of each eligible child and the needs of the family related to enhancing their child's development.

To the maximum extent possible, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate.

Birth to Three programs are based on a statewide, comprehensive, coordinated, interdisciplinary, and interagency model of service delivery. They are administered in Connecticut by the Department of Education, through the **Six Regional Family Service Coordination Centers** across the state.

Who is Eligible?

Infants and toddlers, birth to age three, who are experiencing developmental delays or who have an established condition that has a high probability of resulting in a developmental delay are eligible for services. If there is concern about an infant's or toddler's medical or developmental needs, the parents, or with parental consent, the physician or other health care professional may make a referral for **Birth to Three Services.**

What does Part H Require?

- **Multidisciplinary Assessment:** Each eligible infant or toddler receives a comprehensive multidisciplinary evaluation. The concerns, priorities, and resources of the family are also evaluated relative to the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability.

- **Service Coordination:** Service coordinators act as the single point of contact between the family and all service providers. Service coordination is offered at no cost to the parents.

- **Individualized Family Service Plan (IFSP):** The IFSP is a written plan for providing early intervention services to an eligible infant or toddler and to the child's family. It is based on the evaluation process and developed at an IFSP meeting by the family and an early intervention team. The IFSP represents the outcomes and services needed for the child and family.

- **Health Services:** Health related services that are necessary to enable a child to benefit from other early intervention services, such as catheterization, tracheostomy, tube feeding, and so on, in addition to consultation by physicians with other services providers.

- **Medical Services:** Procedures for diagnostic and evaluation purposes to determine a child's need for early intervention services.

- Assistive technology services and devices

- Audiology and vision services

- Family training, counseling, and home visits

- Nursing and nutrition services
- Occupational, physical, and speech and language therapies
- Psychological and social work services
- Special instruction that promotes the child's acquisition of skills in a variety of developmental areas
- Transportation and related costs

Where do you Request Information and Services?

Call the INFOLINE* toll-free statewide number. An INFOLINE counselor will take basic referral information and fax it to the appropriate Regional Family Service Coordination Center.

INFOLINE: 1-800-505-7000

You may also call the **Regional Family Service Coordination Centers** directly:

Northwest Region
RESCUE
Litchfield, CT
203-567-0863 or 203-791-1904

Northcentral Region
CREC
Windsor, CT
203-298-6188

Northeast Region
EASTCONN
Chaplin, CT
203-455-0503

Southwest Region
CES
Fairfield, CT
203-255-7585 ext. 399

Southcentral Region
ACES
Hamden, CT
203-248-9119

Southeast Region
Project LEARN
East Lyme, CT
203-739-2134

***Additional information available.**

Board of Education and Services for the Blind
(BESB)

What is BESB?

The Board of Education and Services for the Blind (BESB) offers a wide range of services for children and adults with visual impairments. Many services are provided in the home or community by traveling professionals.

Who is Eligible?

A vision report from a qualified professional is required to establish eligibility for any person who is blind or visually impaired. Many of the services offered by **BESB** are free.

What Services does BESB Provide?

- Parent counseling and consultation
- Eye health information
- Home-based infant and preschool services
- Social services consultation
- Training in orientation and mobility skills
- Referral to, and sponsorship for public and private community programs
- Special books, materials, and equipment
- Consultation with local public and private school programs

Board of Education and Services for the Blind

- Low vision evaluations and materials
- Rehabilitation training and specialized instruction
- Referral to vocational and rehabilitation services
- Attendance at Individual Family Service Plan (IFSP) and Planning and Placement Team (PPT) meetings

Where do you Request Services and Information?

Board of Education and Services for the Blind
170 Ridge Road
Wethersfield, CT 06109

Hartford Area: 203-249-8525

Statewide: 1-800-842-4510

Children with Special Health Care Needs
(CSHCN, Title V)

What is CSHCN?

The **Children with Special Health Care Needs (CSHCN)** program coordinates and makes available diagnostic and therapeutic services for children in Connecticut under eighteen years of age who may have, or have been identified as having, special health care needs. These services are provided by qualified professionals or agencies.

Who is Eligible?

In order to qualify for services through **CSHCN**, a family must meet both medical and income eligibility requirements. Children under the age of 18 are medically eligible if they have a disability, including, but not limited to the following:

- Chronic orthopedic problems
- Muscular Dystrophy, Cerebral Palsy, and other neuromuscular conditions
- Congenital heart disease
- Seizure disorders and hydrocephalus
- Cystic Fibrosis, Juvenile Rheumatoid Arthritis
- Myelomeningocele/Spina Bifida
- Cleft lip and palate, hearing and vision losses

CSHCN establishes income eligibility based on family income, medical expenses, and childcare costs.

What does CSHCN Provide?

- Developmental and in-depth evaluations
- Case management and coordination
- Braces, crutches, and other assistive devices
- Medical supplies and other equipment
- Various long-term medications
- Rehabilitative services
- Physical, occupational, and speech therapies
- Hospital outpatient care, medical specialty care, and nursing services
- Laboratory and radiology services
- Emergency care
- Social services, transportation, and consultation with medical professionals
- Consultation to assist with the development of the IFSP (Individual Family Service Plan) or IEP (Individual Education Plan)

Where do you Request Services or Information?

Children with Special Health Care Needs
Department of Public Health and Addiction Services
150 Washington Street
Hartford, CT 06106

Hartford Area: 566-3767
(Spanish-speaking staff are available)

Or call INFOLINE*: 1-800-286-2229
(Maternal and Child Health Information and Referral Service)

*Additional information available.

Commission on the Deaf and Hearing Impaired
(CDHI)

What is CDHI?

The **Commission on the Deaf and Hearing Impaired** (CDHI) serves people of all ages with hearing disabilities, from those with a slight hearing loss to those who are profoundly deaf.

Who is Eligible?

People of all ages who have any degree of hearing loss or impairment are eligible for CDHI services.

What does CDHI Provide?

- Sign language interpreting for situations such as doctor appointments, classroom instruction, Individual Family Service Plan (IFSP) and Planning and Placement Team (PPT) meetings
- Job counseling and placement
- Individual and family counseling
- Equipment loans of Telecommunication Devices for the Deaf (TDDs)
- Education, research, and advocacy

Connecticut Office of Protection and Advocacy for Persons with Disabilities
(P & A)

What is the Office of Protection and Advocacy?

The Connecticut Office of Protection and Advocacy (P & A) provides support to people who have been discriminated against or are experiencing difficulty because of a disability. It also offers them information about programs that serve them, and information about their human and civil rights.

Who is Eligible?

Free services are provided to any person who has a developmental, mental, or physical disability.

What Services are Provided?

- **Advocacy**: Addresses issues of discrimination against people with disabilities, and promotes fundamental changes in the way society responds to persons with disabilities.
- **Client Assistance Program**: Provides advocacy for eligible individuals who wish to apply for vocational services from the Bureau of Rehabilitation, Board of Education and Services for the Blind, or any other facility/program receiving funding under the Rehabilitation Act.
- **Consumer Information**: Provides information, referral services, and short-term advocacy assistance to persons with disabilities. The office also makes informational packets available on issues of disability rights to the general public.

Connecticut Office of Protection and Advocacy

- **Abuse Investigations:** Investigates allegations of abuse and neglect among persons with mental retardation between the ages of 18 and 59.
- **Legal Services:** Represents individuals in cases involving disability rights.

Where do you Request Information and Services?

The Connecticut Office of Protection and Advocacy
60B Weston Street
Hartford, CT 06120

Statewide: **1-800-842-7303***

TDD: **203-566-2102**

*Spanish-speaking staff are available.

Department of Children and Families
(DCF)

What is DCF?

The **Department of Children and Families** (DCF, formerly the Department of Children and Youth Services, DCYS) is responsible for providing services to protect abused or neglected children under age 18, including children with disabilities. **DCF** seeks to help families care for their children in their own homes first, but will use out-of-home placement when in-home services cannot protect children from abuse or neglect. **Physicians are required, by law, to report if they suspect abuse or neglect of their patients.**

Who is Eligible?

Children under the age of 18 are eligible for services to protect them from abuse and neglect, regardless of the family's income.

What does DCF Provide?

- **Family Assessment and Treatment Planning:** An evaluation is conducted to learn the needs of the family, and a plan is designed to assure that these needs are met. Often, **DCF** is part of the Individual Family Service Plan (IFSP) or Planning and Placement Team (PPT) process.

- **Counseling:** Parent Education and Support Centers provide parenting classes, support groups, technical assistance, parent aides, and consultation throughout the state. A toll free Parents Anonymous/CARELINE number is also available (see below).

- **Intensive Family Preservation:** A social worker visits the home several times weekly to observe and monitor the family.

- **Temporary Emergency Shelter:** For children awaiting permanent placement, pending court dates, and so on.

- **Foster Care and Adoption:** Information is provided to prospective adopting parents and parents considering releasing a child for adoption. Special phone number statewide: **1-800-842-6347**.

Where do you Report Suspected Abuse or Neglect, or Request Information?

Department of Children and Families: Offices are open Monday through Friday, 8:30 a.m. - 4:30 p.m. Spanish-speaking staff are available.

Bridgeport	365-6200	Norwich	886-2641
Danbury	797-4040	Rockville	872-6222
Hamden	786-0500	Stamford	348-5865
Hartford	566-4184	Torrington	482-0669
Meriden	238-6185	Wallingford	238-6185
Middletown	344-2120	Waterbury	596-4251
New Britain	827-7137	Willimantic	450-2000

In an emergency, you may also call:

Parents Anonymous/CARELINE: 1-800-842-2288 (24 hours)

Department of Mental Retardation
(DMR)

What is DMR?

The **Department of Mental Retardation (DMR)** coordinates and oversees services for children and adults with developmental disabilities.

Who is Eligible?

DMR services are available to people of all ages who have mental retardation or developmental disabilities. There is an Intelligence Quotient (IQ) guideline of 70 or under for children over 3 years of age and for adults. Often, **DMR** will do thier own assesment of intelligence or cognitive ability. Some services may require a waiting period. Family support grant applicants must meet financial need guidelines.

What Services does DMR Provide?

- Comprehensive case management
- Support for and participation in the Individual Family Service Plan (IFSP) or Planning and Placement Team (PPT) process
- Early Intervention:
    - ➢ For ages **Birth to Three***, through the Regional Family Service Coordination Centers
    - ➢ For ages **Three to Five**, through the local or regional public school system, often within the Special Education* department

*Additional information available.

- Community-based residential programs
- Job training and supported employment
- Respite care, recreation, and other day programs
- Family support grants

Where do you Request Services or Information?

Department of Mental Retardation: Regional offices are open Monday through Friday, 8:30 a. m. - 4:30 p.m.

Region I	Waterbury	596-4371
Region II	Farmington	679-8300
Region III	Willimantic	456-6308
Region IV	Bridgeport	579-6021
Region V	Wallingford	294-5049
Region VI	Waterford	447-0301

Department of Social Services

- Medicaid (Title XIX)*
- Parent Subsidy Aid: grants to assist parents in maintaining severely disabled children at home
- Personal care assistance
- Home and Community Based Waiver*

Where do you Request Information and Services?

Department of Social Services: Offices are open Monday through Friday, 8:30 a.m.- 4:30 p.m. Spanish-speaking staff are available.

Bridgeport	579-6850	New Britain	827-7160
Bristol	583-1671	New Haven	789-7555
Danbury	797-4034	Norwalk	838-2373
Hartford	566-5900	Norwich	823-5000
Manchester	647-1441	Stamford	357-8144
Meriden	238-6200	Torrington	482-5531
Middletown	344-2121	Waterbury	596-4152

*Additional information available.

Early Periodic Screening, Diagnosis, and Treatment
(EPSDT/Health Track)

What is EPSDT?

Early Periodic Screening, Diagnosis, and Treatment/Health Track (EPSDT) is a free health program that provides simple screenings and diagnostic tests, an assessment of any symptoms a child may have, and care and treatment for any health problems that may be identified. These services are reimbursed under Section 1905(G) of Medicaid* (Title XIX).

Who is Eligible?

EPSDT/Health Track serves people under the age of 21 who have a Medicaid card. If, during screening, a diagnosis is made and a course of treatment recommended which is not available under the regular Medicaid program, the treatment would still be covered under **EPSDT/Health Track.**

The billing code used for **EPSDT/Health Track** screenings determines eligibility for the needed services that are identified during the screening. Appropriate billing codes must be used, or services may not be covered.

What Services are Provided by EPSDT?

EPSDT funds medical, clinical, psychological, social, or other services to children. Among these services/providers are:

- Hospitals, clinics, and private nursing care
- Rehabilitation, hospice, and personal care

*Additional information available.

Early Periodic Screening, Diagnosis, and Treatment

- Dietitians, health counselors, and preventive medical care
- Psychologists, case management, and counseling
- Respiratory care, physical and occupational therapy, speech and language therapy, and hearing devices
- Podiatrists, dentists, optometrists
- Medication prescriptions, prosthetic devices, dentures, and eyeglasses
- Transportation

Where do you Request Services or Information?

Bridgeport	579-6733	New Britain	827-7174
Bristol	566-2728	New Haven	789-7718
Danbury	797-4034	Norwalk	838-2373
Hartford	566-3094	Norwich	823-5064
Manchester	647-5899	Stamford	348-6503
Meriden	344-2148	Torrington	566-7440
Middletown	238-6205	Waterbury	597-4099

For a list of health care providers who perform **EPSDT/Health Track** services contact the **Central Office Coordinator: 203-566-3761.**

Healthy Start

What is Healthy Start?

Healthy Start is a state program designed for low income pregnant women, infants, and children who may not have adequate medical insurance. Administered through the Department of Social Services* and the Department of Public Health and Addiction Services, **Healthy Start** expands the coverage of Medicaid* (Title XIX).

Those eligible for **Healthy Start** can receive full medical coverage free of charge. Twenty-four regional **Healthy Start** offices throughout the state assist low income pregnant women and children who may otherwise fall through the cracks in the health care system.

Who is Eligible?

Infants, children under the age of six, and pregnant women who meet certain income guidelines, as determined by each local **Healthy Start** office are eligible for assistance.

What does Healthy Start Provide?

- **Services for Pregnant Women:**
  - ➢ All pre-natal visits and pregnancy-related medical care, including vitamins and prescriptions, tests and laboratory work, labor and delivery, and hospitalizations
  - ➢ Childbirth education and parenting classes
  - ➢ Social work consultations and WIC* referrals
  - ➢ Postpartum check-ups (60 days)

***Additional information available.**

- **Services for Infants and Children under age Six:**
    - ➢ Newborn care and well-child visits
    - ➢ All medical and developmental screening, referrals and treatment, including tests and laboratory work, prescriptions, eyeglasses, and hearing aids
    - ➢ All sick care, hospitalizations, and immunizations
    - ➢ Social work consultations and specialty referrals

Where do you Request Information or Services?

Contact your local **INFOLINE*** or the statewide number: **1-800-203-1234**

Or contact your local **Department of Social Services***: Offices are open Monday through Friday, 8:30 a.m.- 4:30 p.m. Spanish-speaking staff are available.

Bridgeport	579-6850	New Britain	827-7160
Bristol	583-1671	New Haven	789-7555
Danbury	797-4034	Norwalk	838-2373
Hartford	566-5900	Norwich	823-5000
Manchester	647-1441	Stamford	357-8144
Meriden	238-6200	Torrington	482-5531
Middletown	344-2121	Waterbury	596-4152

*Additional information available.

Home and Community Based Waiver
(Katie Beckett/Medicaid Waiver)

What is the Home and Community Based Waiver?

The **Home and Community Based Waiver** program is also known as the Katie Beckett Waiver or the Medicaid Waiver. It is administered as part of Medicaid* through the Department of Social Services*. This program is designed for individuals who have medical needs which require some level of skilled care.

The intent of the program is to keep individuals living in the home, rather than placing them in a skilled care facility. Families who may not be eligible for standard Medicaid coverage, may be able to receive Medicaid assistance for their child through this program.

Who is Eligible?

Any individual under the age of sixty-five who has identified disabilities or special health care needs is eligible if they meet both the medical and income eligibility requirements.

- **Medical Eligibility:** To determine medical eligibility, a nursing assessment must be completed by a licensed home health care agency, and will be paid for by Medicaid. In order to qualify, the individual must require a skilled level of care by a Registered Nurse, a Licensed Practical Nurse, or a Home Health Aide. The cost of the care must be less than the cost of placing that person in a skilled care facility.

- **Income Eligibility:** Income eligibility is based on the individual's income and assets, rather than the income and assets of the family.

*Additional information available.

Even though parents and other family members will not be covered by the **Home and Community Based Waiver**, a standard Medicaid application will need to be completed. With only 125 waivers in Connecticut, it is important to place an individual's name on the waiting list as early as possible. The current waiting period is approximately 4 years.

What Services are Provided?

The **Home and Community Based Waiver** program offers coverage for the same services as regular Medicaid/Title XIX*. In addition, home nursing care, some home equipment costs, and case management services are provided. There is a predetermined cap on the amount of dollars that can be spent per year for each individual in the program.

Where do you Request Application or Information?

Medicaid Waiver Coordinator
Department of Social Services
Alternate Care Unit
25 Sigourney Street
Hartford, CT 06106

Hartford Area:	**203-424-5187**
Statewide:	**1-800-445-5394**

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*Additional information available.

INFOLINE

What is INFOLINE?

INFOLINE offers Connecticut residents information about, and referrals to, services in their community. A professional caseworker counsels the caller and directs him or her to the appropriate resources.

Who is Eligible?

Any resident of the state of Connecticut may use the services of **INFOLINE.**

What does INFOLINE Provide?

- Information about crisis intervention services
- Information and referrals to an array of services such as child care, early intervention, and maternal and child health care
- Human services information on education, housing, employment, welfare, and transportation

Where do you Request Information or Services?

Statewide number to all regions:	**1-800-203-1234**
Statewide number for Birth to Three:	**1-800-505-7000**

Southwestern (24 hour service)

Bridgeport	333-7555	Spanish line	335-5311
Norwalk	853-2525	Spanish line	853-1177
Stamford	324-1010	Spanish line	964-9844

South Central (Monday-Friday, 9 a.m.-9 p.m.)	
Ansonia and Naugatuck	734-2573
New Haven, Milford, Guilford, and Madison	867-4150
Meriden and Wallingford	235-7974
Eastern (Monday-Friday, 8 a.m.-9 p.m.)	
New London	886-0516
Middletown	346-6691
Old Saybrook	388-9941
Danielson and Killingly	774-7257
Putnam	928-6577
Willimantic	456-8886
North Central (24 hour service)	
Hartford	522-4636
Bristol	584-2244
New Britain	225-4233
Andover and Stafford	872-2626
Northwest (24 hour service)	
Danbury	778-4636
Waterbury	759-2000
New Milford	355-0023
North Canaan	824-5371
Torrington	482-9471

Spanish-speaking staff and Telecommunication Devices for the Deaf (TTDs) are available in each office.

Medicaid
(Title XIX)

What is Medicaid?

A federal and state program administered by the Department of Social Services*, **Medicaid** pays for the medical expenses of those who are eligible.

Who is Eligible?

People who receive AFDC* or State Supplement (through the Supplemental Security Income* program) assistance automatically qualify for **Medicaid**. People who have high medical bills, but do not meet the income guidelines for AFDC or the State Supplement may also receive assistance under certain circumstances. The Department of Social Services determines eligibility on the basis of family size, income, assets, and need.

What Services are Covered by Medicaid?

- Inpatient hospital services
- Outpatient hospital services
- Physicians' services
- Nurse-Midwife services
- Rural health clinic services
- Laboratory and x-ray services
- Nurse Practitioners' services
- Family planning services and supplies

*Additional information available.

- Nursing facility services and home health services for those age 21 or older
- Early and Periodic Screening, Diagnosis, and Treatment (EPSDT*) for those under age 21

Where do you Request Services or Information?

Department of Social Services: District offices are open Monday through Friday, 8:30 a.m. - 4:30 p.m. Spanish-speaking staff are available.

Bridgeport	579-6850	New Britain	827-7160
Bristol	583-1671	New Haven	789-7555
Danbury	797-4034	Norwalk	838-2373
Hartford	566-5900	Norwich	823-5000
Manchester	647-1441	Stamford	357-8144
Meriden	238-6200	Torrington	482-5531
Middletown	344-2121	Waterbury	596-4152

*Additional information available.

Special Education and Related Services
The Individuals with Disabilities Education Act (IDEA)

What are Special Education and Related Services?

Special Education refers to specially designed instruction, at no cost to parents or guardians, to meet the unique needs of a child with a disability, as identified under P.L. 94-142 and the Individuals with Disabilities Education Act (P.L. 101-476). Instruction may occur in the classroom, in the home, in hospitals and institutions, and in other settings.

Related Services refers to transportation and any other developmental, corrective, or supportive services that may be required so that a child with a disability will benefit from special education.

Special Education and Related Services are administered through the Local Educational Authority (LEA) or board of education in each town or region. To the maximum extent possible, schools must educate children who have disabilities with their peers who do not have disabilities. This is referred to as **mainstreaming, least restrictive environment, or inclusion.**

Parents have the right to obtain an independent evaluation; consent or object to the identification, evaluation, or placement of their child; and request an impartial due process hearing and/or mediation if they are in disagreement with the school system.

Physicians may play a key role in the development of a child's educational program when disabilities and/or special healthcare needs have been identified.

Who is Eligible?

Children from ages 3 to 21 who have disabilities and/or special health care needs that interfere with their ability to benefit from their education are eligible. Parents, teachers, or other professionals can make a referral for **Special Education and Related Services** when a child shows persistent learning difficulties. In Connecticut this includes children with:

- Speech and language impairments
- Learning disabilities and attention deficit disorders
- Mental retardation and autism
- Orthopedic impairments
- Social and emotional adjustment problems
- Other health impairments and physical disabilities
- Neurological impairments and traumatic brain injuries
- Vision and hearing impairments
- Multiple handicaps

What does IDEA Require?

- Comprehensive, multidisciplinary, and non-discriminatory evaluations.
- An Individual Educational Plan (IEP) for each child with a disability, which represents the expected outcomes and services/resources necessary for the child to benefit from special education and related services. The IEP is developed at a Planning and Placement Team (PPT) meeting with parents, school personnel, and other service providers, such as physicians.

- Transition assistance for students moving beyond high school, including post-secondary education, vocational training, integrated employment, adult services and education, independent living, and community participation.

- Related services which might include, but are not limited to:
    - ➢ Medical services for diagnostic or evaluation purposes
    - ➢ Speech pathology and audiology
    - ➢ Psychological and counseling services
    - ➢ Physical and occupational therapy
    - ➢ Therapeutic recreation and rehabilitation counseling
    - ➢ School health services, school social work services, and parent counseling and training
    - ➢ Assistive technology devices and services which are used to increase, maintain, or improve the functional capabilities of individuals with disabilities

Where do you Make a Referral or Request Information?

The Department of Special Education or Pupil Personnel Services within the local or regional public school district. Additional information may be obtained from:

State Department of Education
Special Education and Pupil
Personnel Services
25 Industrial Park Road
Middletown, CT 06457

203-638-4265

Special Education Resource
Center (SERC)
25 Industrial Park Road
Middletown, CT 06457

203-638-1485

Special Supplemental Food Program for Women, Infants, and Children
(WIC)

What is WIC?

The **Special Supplemental Food Program for Women, Infants, and Children (WIC)** is a federally funded food and nutrition education program administered by the Department of Public Health and Addiction Services. It is designed to improve the nutrition of pregnant women, postpartum or nursing mothers, and children up to the age of five.

WIC enables participants in the program to attain the foods necessary for a healthy and balanced diet. By helping to prevent malnutrition, the program also helps prevent further health problems or developmental delays in young children.

Who is Eligible?

Pregnant women, postpartum or nursing mothers, infants, and children up to age five who have been identified by a health professional as being at "nutritional risk," and who meet the income guidelines established by WIC are eligible for assistance.

What does WIC Provide?

- Food checks to purchase specific foods
- Nutritional counseling and referrals to other health services
- WIC/Farmers Market Coupons for fresh produce

Where do you Request Information and Applications?

Local WIC Offices: Hours vary from office to office.

Bridgeport	576-8006* 576-8075	Norwalk	853-1322*
		Norwich	889-1365*
Bristol	585-3490*	Putnam	928-3660*
Danbury	797-4629*	Rockville	875-0602
East Hartford	291-7323*	Shelton	924-1831
Hartford	722-8060*	Stamford	977-4385*
Meriden	630-4245*	Torrington	489-1138
Middletown	344-8014*	Waterbury	574-6785*
New Britain	224-5297*	Willimantic	423-1012*
New Haven	789-3563* 784-0236* 773-5007* 785-5150*		

* Spanish-speaking staff available.

Supplemental Security Income
(SSI)

What is SSI?

A federal income maintenance program for those who are aged, blind, and/or disabled, **Supplemental Security Income (SSI)** is administered by the Social Security Administration. The **SSI/Disabled Children Program** provides money each month to children with disabilities whose families are in need.

Who is Eligible?

Children and adults who are aged, blind, or disabled*, and who meet certain income and asset guidelines are eligible. It is important that all information documenting the patient's disabilities be made available when applying for **SSI**. Applicants can appeal through the Social Security Administration office if their applications are denied.

Where do you Request Information and Applications?

Social Security Administration: Offices are open Monday through Friday, 9:00 a.m. to 4:00 p.m.

Statewide: 1-800-772-1213 **TDD: 1-800-325-0778**

Ansonia	735-6201	East Hartford	240-3761
Bridgeport	365-8452	Hartford	240-3713
Bristol	584-2716	Meriden	238-0346
Danbury	748-3569	Middletown	347-8562

***Additional information available.**

Supplemental Security Income

Social Security Administration Offices (continued)

New Britain	229-4844	Stamford	359-0030
New Haven	773-2160	Torrington	489-1633
New London	443-8456	Waterbury	756-7476
Norwich	886-7118	Willimantic	423-6386
South Norwalk	849-1911		

The Family Center

What is The Family Center?

The Family Center, at Newington Children's Hospital, offers support to families of children with disabilities and special health care needs. **The Family Center** is made possible through funding from The Hartford Foundation for Public Giving, the Connecticut Developmental Disabilities Council, and Newington Children's Hospital.

Who is Eligible?

Any parent who has a child with disabilities or special health care needs may make use of the services that **The Family Center** offers.

What Services and Supports are Offered?

- Informal parent-to-parent support and contact with a statewide network of parents who have children with disabilities and special health care needs
- Answering questions about resources, agencies, and programs, and how to locate and apply for services
- Information about and technical assistance for accessing insurance and publicly funded health care financing including Medicaid and Social Security
- Advocacy for fair hearings and insurance appeals
- Support for families in learning how to communicate effectively with professionals and how to participate in meetings about their children
- Sponsorship of opportunities for formal training through conferences and workshops
- A book and video resource library

Where do you Request Information or Refer Parents for Support?

The Family Center
Newington Children's Hospital
181 East Cedar Street
Newington, CT 06111

203-667-5288*

*Spanish-speaking staff are available.

Appendices

Appendix A
Other Agencies that May be of Help to You and Your Patients

Association for Retarded Citizens/Connecticut (ARC)	West Hartford	953-8335
Casey Family Services	Statewide	1-800-332-6991
Connecticut Alliance for the Mentally Ill (CAMI)	Storrs	456-3795
Connecticut Anti-Hunger Coalition (CAHC)	Hartford	522-7762
Connecticut Association of Child Caring Agencies	New Britain	225-5275
Connecticut Association for Human Services (CAHS)	Hartford	522-7762
Connecticut Coalition Against Domestic Violence (CCADV)	Hartford	524-5890
Connecticut Council of Family Service Agencies	Greenwich	869-4848
Connecticut Department of Public Health and Addiction Services (DPHAS)	Hartford	566-4800
Connecticut Parent Advocacy Center (CPAC)	East Lyme	739-3089
	Statewide	1-800-445-2722
Connecticut Traumatic Brain Injury Association	Rocky Hill	721-8111
Connecticut Youth Services Association	No. Grosvenordale	923-2829

Appendix A: Other Agencies

Coordinating Council for Children in Crisis (CCCC)	New Haven	624-2600
Easter Seal Society of Connecticut	Statewide	1-800-874-7687
	TDD	228-2091
Lead Poisoning Prevention Program	Hartford	566-5808
Special Education Resource Center (SERC)	Middletown	632-1485
Special Education Technology Lab	Storrs	1-800-237-7951

Also check your local listings for:

- Family Service Agencies
- Child Guidance Clinics
- Mental Health Centers
- Legal Assistance Programs
- Parent Education and Support Centers

Appendix B
Glossary of Abbreviations

AFDC	Aid to Families with Dependent Children
BESB	Board of Education and Services for the Blind
CSHCN	Children with Special Health Care Needs
CDHI	Commission on the Deaf and Hearing Impaired
DCF	Department of Children and Families
DMR	Department of Mental Retardation
DSS	Department of Social Services
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
IDEA	Individuals with Disabilities Education Act (P.L. 101-476)
IEP	Individual Education Plan
IFSP	Individual Family Service Plan
LEA	Local Education Authority
P & A	Connecticut Office of Protection and Advocacy for Persons with Disabilities
PPT	Planning and Placement Team
SSI	Supplemental Security Income
TDD	Telecommunication Device for the Deaf
WIC	Supplemental Food Program for Women, Infants, and Children

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APPENDIX C

Please rate the following statements on a scale of 1 through 5 by circling your chosen response:

1 indicates that you **strongly disagree** with the statement
2 indicates that you **somewhat disagree** with the statement
3 indicates that you are **neutral** about the statement
4 indicates that you **somewhat agree** with the statement
5 indicates that you **strongly agree** with the statement

	A. *CONTENT*	Strongly Disagree		Neutral		Strongly Agree
1.	Objectives of the training were met.	1	2	3	4 **40%**	5 **60%**
2.	All topics on the agenda were addressed.	1	2	3 **10%**	4 **70%**	5 **20%**
3.	Time was well organized.	1	2 **10%**	3 **10%**	4 **50%**	5 **30%**
4.	The **information** gained is relevant and can be applied to my work situation.	1	2	3 **10%**	4 **30%**	5 **60%**
5.	This **experience** will enhance the way I deliver services to patients and their families.	1	2	3	4 **30%**	5 **70%**
6.	I have a better understanding of the role a physician might have in a child's educational program.	1	2	3 **10%**	4 **10%**	5 **80%**
7.	The concepts of Family Centered Care and Team Process are applicable to my work setting.	1	2	3	4 **30%**	5 **70%**
8.	I am more aware of education law as it pertains to children with disabilities and special healthcare needs.	1	2	3	4 **40%**	5 **60%**

B. *PRESENTATIONS*

		Strongly Disagree		Neutral		Strongly Agree
1.	The presenters were well prepared and organized.	1	2	3	4 **30%**	5 **70%**
2.	The presenters communicated in a clear and understandable manner.	1	2	3	4 **50%**	5 **50%**
3.	The presenters valued my input.	1	2	3	4 **50%**	5 **50%**
4.	The presenters addressed my questions and concerns.	1	2	3 **20%**	4	5 **80%***
5.	The materials (e.g., handouts, videos, manuals) were relevant to the training.	1	2	3	4 **20%**	5 **80%**

*** Only 5 residents responded to this question due to printing error on some f**

C. *HOME VISIT*

1. My patient was from:
__ Continuity Clinic
__ Children with Special Health Care Needs Clinic
__ The Family Center
__ Other: ____________________________________

2.	The home visit was easy to arrange.	1	2 **10%**	3	4 **20%**	5 **70%**
3.	I found the parents to be open and available for discussions about their child.	1	2	3	4	5 **100%**
4.	I gained information about the child's needs in the home.	1	2	3	4 **20%**	5 **80%**
5.	I gained a sense of the **positive** aspects of this child's life from the family's perspective.	1	2	3 **10%**	4 **30%**	5 **60%**
6.	I gained a sense of the parent's concerns regarding their child.	1	2	3	4	5 **100%**

		Strongly Disagree		**Neutral**	**Strongly Agree**	
7.	I discovered ways in which a physician might be helpful to the family and child.	1	2	3	4 **40%**	5 **60%**

D. ***PROGRAM VISIT *****

		Strongly Disagree		**Neutral**	**Strongly Agree**	
1.	I gained information about the child's needs in the school/ child care setting.	1	2	3	4 **50%**	5 **50%**
2.	I gained a sense of the **positive** aspects of this child's life from the teacher's perspective.	1	2	3 **50%**	4 **50%**	5
3.	I gained a sense of the teacher's concerns regarding this child's special needs.	1	2	3 **75%**	4 **25%**	5
4.	I discovered ways in which a physician may be helpful to the child and the staff at the school or child care program.	1	2	3 **25%**	4 **50%**	5 **25%**

**** Only 4 of the 10 residents who returned this survey completed a program**

E. ***OVERALL***

1. What did you find most helpful about this experience?

I learned a lot about the family and child with special health care needs secondary to chronic illness or disability.

It provided me with insight into the difficulties faced at home living with a disabled child.

The home visit was the most useful. The hand out provided was extremely useful in addition to the videos.

The most useful part of this experience was the understanding I gained about how the family can really be the major player in the care of a child with special needs. I also got an idea about how complicated the process can be and how it has to be coordinated.

To see the child more from the family perspective than medical problem perspective.

Home visit.

Knowledge about resources in the community for kids with special needs. Understanding parents feelings and frustrations with health care system in dealing with these needs.

To see the child in his home setting and talk to the parent in a non-hospital setting.

The home and school visits.

2. Did you have any difficulties during this experience? If so, please describe them fully.

Scheduling family visits because of the holiday.

The only difficulty encountered was in trying to get an appointment for the home visit.

Time constraints and need to do things very quickly presented minor difficulties.

I had no difficulties at all. The parents and the day care facility instructors were very cooperative and gave me all the information I needed without really feeling that I was intruding.

I felt uneasy to go to the home, but I am happy to have had the opportunity to do so.

Scheduling school visit due to holidays and weather cancellations.

3. What additional information or opportunities would you like to see included in this training?

School program visit and follow up in clinics.

Could be useful to spend a little more time observing how exactly family problems are managed in real situations.

Video tape training and feedback session with parent/trainer.

An opportunity to see how the Early Intervention Program functions and to see the therapists and coordinators working on a case would be useful. It is a part of the picture we never really get to see - we just hear about it as doctors.

Unfortunately, it was not easy or possible to find a child in school and understand the problems at school better, because the patient was only a one year old.

A visit to a special needs school.

I think that the videos shown are good, but that the information gained from them is of a general nature and the time to see them could be compacted in a single session, and some more time used for additional clinic or field experiences.

4. What might you do differently in your practice as a result of this training?

I'll have a better sense of children with chronic illness needs, so I will be able to refer them to proper agency to help them meet their needs.

I would like to arrange a home visit to the home of disabled patients in my clinic to better assess their needs and strengths.

Would view problems with a family centered attitude and deal with them in a way that is best suited for the child and family.

Become more involved in school setting.

I think I will definitely involve parents of children with special needs more in their management in the inpatient setting. I'll also be able to approach the question of care of children after discharge from the hospital and as outpatients with more understanding of the programs they are a part of.

More culturally sensitive (get information about usually unknown home remedies that are used by certain families).

Try to keep current on the information of all the supportive programs offered to these chronically ill children and families.

Refer parents/patients to community resources.

Talk at greater length with the parents. Offer services of support and information. Try to coordinate services.

Give more time to discuss special issues that apply to children with disabilities that are hard to address in a regular well child visit/sick visit.

5. In your own words please complete this phrase: This experience provided me...

An opportunity to learn from the family of a child with chronic illness. A better sense of their needs and how these can be met.

With a better understanding of the difficulties faced in caring for a disabled child.

The knowledge about family centered care in depth especially recognition of family strengths and individuality and coordination of various service systems tailored to family needs.

Of a particular parent-oriented perspective which I found to be helpful in giving me a well rounded view of the MD's role.

With a window through which I got a glimpse of how life can be like with a child who has special needs.

Time to talk with a previously abused (raped) mother in a safe environment about her experience and see the environment my patient is living in.

With better insight of what the available programs offer to the families.

With an understanding of what parents with kids with special needs endure, their frustrations, and ways of dealing with them.

With a unique opportunity to see and feel a part of the world of a family with a child who has special needs and incorporate a more humane aspect to my overall thinking.

With perspectives from parents and teachers of the needs and roles that children with special needs play in the family and school setting. Perspective about the strong emotional and daily basis functioning impact of such a child in the family life.

6. **Important:** Please list those needs identified by the family or program staff that require further attention:

According to the child's mother all his needs are being provided by different services at present. If ever she is going to have a problem, she knows where to go and ask for assistance.

The family felt that the child had been misdiagnosed and little information was given as to the diagnosis. The requested contact with other parents who have disabled children. Information for child care and for funds for a child with special health needs.

Health concerns: possibility of seizures, need for information about ENT services locally instead of Boston. Educational concerns: possibility of home computer. Financial concerns: need for beeper for easy accessibility, unfriendly letter from NCH regarding bill payment.

Speech therapy for some more time. More involvement of the pediatrician.

Possibly in a very sensitive way counseling to the grandmother of my patient may be offered, but this should not be forced and I may address this in a suitable situation.

Legislation to be aware of how needy these children are (and family as well). Continued encouragement not for the patient only, but for the families as well.

Increased awareness in school of kids condition and more positive action in dealing with his weaknesses. Increased awareness in medical professional community of community resources for kids with special needs.

APPENDIX D

Survey of Connecticut Pediatricians On Early Intervention and Special Education

For Information, Please Contact:
Physicians Training Project
Division of Child and Family Studies
Department of Pediatrics
University of Connecticut Health Center
Suite A200 - Farm Hollow
309 Farmington Avenue
Farmington, Connecticut 06032
(203) 679-4632

The Physicians Training Project is funded as a model demonstration grant from the U.S. Department of Education, Office of Special Education Programs, Division of Personnel Preparation Grant #H029K203

SURVEY OF CONNECTICUT PEDIATRICIANS
On
Early Intervention and Special Education

Physicians Training Grant
Division of Child and Family Studies
University Of Connecticut Health Center

The physician who provides medical care to a child with disabilities plays a key role in the ongoing support of the child and his/her family. The literature on early intervention and special education has often addressed the role of the pediatrician or family physician (Brewer, McPherson & Magrab, 1989; Coury, 1990; Howard, 1982; McInerney, 1984; Scott, et al, 1993; Shonkoff, Dworkin & Leviton, 1979), and federal law acknowledges the importance of the physician and health services by including them within the statewide system of early intervention. Unfortunately, however, few states have successfully integrated the health system, and the pediatrician or family-practice provider, the early intervention system. As a child ages into the special education system (age 3-21) the gap between the child's medical care and educational services only increases (Eaton, Coury & Kern, 1989). One reason for this situation is physicians' lack of awareness and knowledge about their role in state systems of early intervention and special education. This is not surprising, considering that both the preservice and inservice training of pediatricians place very little emphasis on the care and management of a child with disabilities (Scott, et al., 1993). However, the importance of a multidisciplinary team for early intervention, as stressed by Part H of the Individuals with Disabilities Act (IDEA), has stimulated interest in improving this situation (e.g., Coury, 1990; Peter, 1992; Schwab, 1991).

The American Academy of Pediatrics (AAP) has developed comprehensive medical education programs to meet the needs of pediatricians in practice. In 1978 a specialty task force released a report on pediatric education, assessing the health needs of children and the educational needs of the pediatricians who serve them. Among its conclusions, the task force found that: 1) all pediatricians should have the skills to cope with biosocial and developmental problems; and 2) residency programs need to emphasize training in the provision of care to children with chronic handicapping conditions (The Task Force on Pediatric Education, 1978). That same year, the Office of Special Education and Rehabilitation Services of the U.S. Department of Education funded the Academy to develop an inservice training curriculum that was used with over 5,000 primary care physicians who serve children with disabilities (Powers & Healey, 1982). Since then, however, few programs have had such scope and ambition (Coury, 1990).

For many years now, researchers have advocated continuing education programs for pediatricians on the care children with disabilities (Dworkin, Shonkoff, & Leviton, 1979; Haggerty, 1974). Among their recent recommendations is educating the pediatrician to provide a medical "home" for the primary medical care of each child (Koop, 1987). This home should be comprehensive, coordinated, family-centered, and community-based. This concept has been endorsed by both the AAP and the Bureau of Maternal and Child Health (National Center for Networking Community-Based Services, 1989). In order to provide such a home, physicians must know of, and be involved with, public programs which serve children with disabilities. A survey to determine the extent of the physicians' knowledge of, and involvement with, public programs which serve children with disabilities is an important first step for those seeking to improve the involvement of physicians in the statewide early intervention and special education system.

PURPOSE OF THE STUDY

The purpose of this survey was to assess the current knowledge of, and involvement of pediatricians with both the early intervention and special education systems, and the other public programs which serve these children. The study addressed the following areas: 1) The pediatricians' background and current practice; 2) The pediatricians' knowledge of, and experience, with children with disabilities; 3) The pediatricians' understanding of public programs and their relationship to the care of children with disabilities; and 4) The pediatricians' interest in more information and training on children with disabilities, and what type of training would best assist them.

METHOD

Sample

All 813 pediatricians currently listed as members of the Connecticut Academy of Pediatrics were asked to participate in this investigation. The Connecticut chapter of the Academy of Pediatrics provided the mailing labels for these pediatricians and the survey team sent them a letter describing the purpose of the survey.

Procedures

The Division of Child and Family Studies, with assistance from an advisory board, developed a survey consisting of a checklist of thirty-three questions in four areas of inquiry, with a self-mailer for easy return of the survey (Appendix A).

The survey was sent to the 813 pediatricians in mid-April, 1993. A letter explaining the purpose of the survey was also sent with the survey. The University of Connecticut Medical School authorized this letter, which was signed by Dr. Mary Beth Bruder, Associate Professor in the Department of Pediatrics and Director of the Division of Child and Family Studies; Dr. Robert Greenstein, Professor in the Department of Pediatrics and Director of the Division of Genetics; and Dr. Lawrence Kaplan, Assistant Professor in the Department of Pediatrics and the Director of the Children with Special Health Care Needs at Newington Children's Hospital (an affiliate of the University of Connecticut). Dr. Kaplan is also the chair of the Connecticut Academy's division on children with disabilities. In addition to explaining the survey's purpose, the letter also requested the return of the survey by mid-May. After receiving 248 completed surveys by May 15, a second mailing to the remaining 565 non-responding pediatricians was mailed in early June.

RESULTS

Background demographics

Of the 813 pediatricians addressed, 311 returned completed surveys. Thirty-six surveys were returned because the pediatrician was no longer practicing or was deceased. Of the corrected Connecticut Academy membership of 777, then, the 311 returned surveys represent a return sample of 42.9%.

Characteristics of respondents

The average survey respondent (N=311) graduated in 1972 and completed residency in 1976. Medical school graduations for this survey population ranged from 1929 to 1992. Completion of pediatric residency ranged from 1931 to a projected date of 1995. The median date of graduation for this population was 1975. Two hundred and fifty-nine (83.3%) respondents were Board Certified in Pediatrics (Figure 1), and 25 physicians were Board Eligible (Figure 2). Pediatricians who are Board Eligible have completed their residency training and are ready to take the written residency exam, while physicians who are Board Certified have completed their residency training and successfully passed the written residency exam. Although Connecticut has no continuing education requirements, the American Academy of Pediatrics requires continuing education units for national accreditation.

Description of current practice

Two hundred and eleven respondents (67.8%) have a full-time practice, and 46 (14.8%) are in part-time practice; 54 (17.4%) did not answer the question (Figure 3). The pediatricians spend on average 81% of their time in clinical practice. Fifty-three percent of the pediatricians are either in group or solo private practice and 11% are hospital based, while the other 36% have either government or academic practice (Table 1). A majority of the responding pediatricians (79.1%,N=246) say that they accept Medicaid patients (Figure 4). Of those 246 pediatricians who do accept Medicaid patients, 42.7% perform Early Periodic Screening, Diagnostic and Testing (EPSDT). (Figure 5)

Training on children with disabilities

The survey results showed medical schools provided training on children with disabilities to only 24.5% of the respondents (Table 2). Fifty-six percent of the pediatricians reported that their pediatric residency programs provided them with training on children with disabilities (Table 3). Table 4 and Table 5 show the relationship between the pediatricians' graduation dates from medical school, whether or not they received disabilities training, and the relationship between the two. The pediatricians' Medical School graduation date was grouped by decade, with 1920 and 1930 as a single group; they also grouped pediatric residency graduation by decade, with 1920-1940 as a single group for completion of residency training. With the exception of 1920s-1930s (N=6) and 1990s (N=7) the pediatricians' Medical School training for disabilities in children increased in each decade. However, the residency/training by decade had a different distribution pattern: the percentage of pediatricians receiving disabilities training increased through the 1960s, decreased in the 1970s, and increased again during the 1980s.

Coordination of services

The questionnaire asked respondents if they coordinated services for children in their practice who receive special education or early intervention services. Two hundred and sixteen (69.5%) said they did coordinate services, 76 (24.4%) said they didn't, while 19 (6.1%) did not answer the question (Figure 6). The survey also asked the pediatrician if he or she had ever directly participated in developing either an Individual Education Plan (IEP) or an Individual Family Service Plan (IFSP). The IFSP (for ages up to 3) and IEP (for ages 3-21) are legal documents containing detailed information on the education of the child with disabilities. One hundred and one respondents (32.5%) had participated in the development of an IEP (Figure 7), while only 25 (8%) had participated in an IFSP (Figure 8).

Legislation concerning children with disabilities

The survey asked a two-part question regarding the pediatricians' knowledge of Part H of Individuals with Disabilities Education Act. When asked if they had heard of Part H, 23.5% (N=73) answered yes, while 72% (N=224) answered no (Figure 9). Table 6 shows the cross-tabulation of pediatricians who coordinate services to children with disabilities and whether they had heard of Part H. This tabulation shows that of the 216 pediatricians who said they had provided coordination of services to children with disabilities, 60 had heard of Part H. Forty percent of those pediatricians with an academic appointment to the University of Connecticut had heard of Part H, 17.2% with an academic appointment to Yale had heard of Part H, and 19.6% of pediatricians in private practice had heard of Part H. The pediatricians were asked to answer the second part of the Part H question only if they had heard of Part H. The question was how informed were the pediatricians about Part H . The survey provided three choices for an answer: "well informed", "somewhat informed", and "slightly informed"; as well as a description of what each choice meant (Appendix A). Of those who said they had heard of Part H (N=73), 43.8% considered themselves "somewhat informed", 38.4% saw themselves as "slightly informed", while 17.8% described themselves as "well informed" (Figure 10).

The questionnaire asked a similar two part question about the Americans with Disabilities Act (ADA). The vast majority of the pediatricians 80.1% (N=249) said they had heard of ADA (Figure 11). One hundred percent of those pediatricians with an academic appointment to the University of Connecticut had heard of the Americans with Disabilities Act, and 85.7% of pediatricians with an academic appointment to Yale had heard of ADA, while 77.1% of those pediatricians in private practice had heard of ADA. Of those pediatricians who had heard of ADA, 8.4% (N=21) considered themselves "well informed" and 39.9% (N=99) "somewhat informed", 51% (N=127) considered themselves "slightly informed"(Figure 12).

Knowledge of public programs

The pediatricians then rated their understanding of fourteen different public programs and their relationship to the care to children with disabilities. Table 7 shows each public program surveyed and the pediatricians' level of understanding of the following programs: Aid to Families with Dependent Children; Birth to Three Service Coordination; Board of Services for the Blind; Children with Special Health Care Needs; Commission on the Deaf and Hearing Impaired; Department of Income Maintenance (Social Services); Department of Mental Retardation; Department of Children and Families; Early Periodic Screening, Diagnosis and Treatment; Healthy Start; Medicaid; Special Education; Supplemental Social Security (SSI); Women, Infants and Children (WIC).

Training needs

The last section of the survey explored the responding pediatricians' level of interest in learning more about any subject pertaining to young children with disabilities under Part H of IDEA, as well as their preferred format for learning. Of the 311 respondents, 79.7% (N=249) were interested in learning more about any subject pertaining to young children with disabilities under Part H of IDEA (Figure 13). Those interested in learning more were asked to rank the format choices from one to eight, with one the most preferred, eight the least preferred. Brochures were the most preferred training format (mean=2.5), with grand rounds (mean=3.01) the next preferred. The least preferred method was "Mini-Fellowship/Post Graduate Work". The lower the mean reveals the more preferred format. See Table 8 for the order of preference of all surveyed formats.

DISCUSSION

The survey results demonstrated that most pediatricians are uninformed about Part H of IDEA, as well as other public programs which serve children with disabilities and their families. This is not surprising since this sample also reported a lack of training regarding children with disabilities within their medical school and residency training programs. These data support similar findings by others also interested in the involvement of physicians with children with disabilities (Dworkin, Shonkoff, & Leviton, 1979; Scott, et al., 1993).

While a lack of knowledge on programs for children with disabilities was well documented on this sample, two areas are worth noting. First, most of the responding pediatricians reported that they considered themselves as service coordinators for the children with disabilities in their practice. However, few reported having heard of Part H of IDEA. This lack of knowledge about the Part H program obviously limits the pediatrician's ability to provide comprehensive service coordination services to the children in his practice who have disabilities. Secondly, although most of the respondents accepted Medicaid patients, less than half reported that they performed EPSDT checkups. The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program, is part of the Medicaid program for children, and as such, was initiated in the late 1960s. EPSDT mandates early and periodic medical, dental, vision and developmental screening, diagnosis and treatment of all children and youth under 21 years of age who are Medicaid eligible. EPSDT is also known as Health Track in Connecticut. The obvious lack of knowledge and practice with EPSDT suggests a lack of full health services for Medicaid eligible children in Connecticut.

Perhaps one of the survey's most significant findings was the large number of physicians interested in learning more about subjects pertaining to young children with disabilities and services under Part H of IDEA. The respondents whole-heartedly endorsed the need for information on public programs for children with disabilities in Connecticut. The results of this survey strongly support a need for increased information and training to improve the pediatricians' ability to provide more comprehensive care to children with disabilities.

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List of Tables

TABLE 1
Primary Type of Practice

	N	%
SOLO PRIVATE PRACTICE	48	15.4%
GROUP PRIVATE PRACTICE	117	37.6%
HOSPITAL BASED	35	11.3%
MANAGED CARE PRACTICE	13	4.2%
ACADEMIC UCONN	25	8.0%
ACADEMIC YALE	30	9.6%
ACADEMIC OTHER	3	1.0%
GOVERNMENT	8	2.6%
MISSING	32	10.3%

TABLE 2
Did the Responding Physician's Medical School Training Include Specific Curriculum on Children with Disabilities

	N	%
YES	76	24.4%
NO	225	72.3%
MISSING	10	3.2%

TABLE 3
Did the Responding Physician's Pediatric Residency Include Specific Training on Children with Disabilities

	N	%
YES	172	55.3%
NO	129	41.5%
MISSING	10	3.2%

TABLE 4
Medical School Graduation and Receipt of Training in Medical School on Children with Disabilities

	Training in Med School	No Training
1920 - 1939	1	5
1940 - 1949	0	14
1950 - 1959	5	21
1960 - 1969	12	39
1970 - 1979	21	57
1980 - 1989	33	80
1990 - 1992	1	6

TABLE 5
Year Completed Residency and Receipt of Training on Children with Disabilities During Residency

	Training in Residency	No Training
1920 - 1949	4	6
1950 - 1959	11	13
1960 - 1969	20	12
1970 - 1979	45	38
1980 - 1989	68	43
1990 - 1992	20	15

TABLE 6
Coordination of Services and Knowledge of Part H

	Heard of Part H	Have not Heard of Part H
COORDINATE SERVICES	60	156
DOES NOT COORDINATE SERVICES	11	63

TABLE 7
Physicians' Knowledge of Public Service Programs

	Well Understood	Somewhat Understood	Not Understood	Need More Information	Missing
Aid to Families with Dependent Children	22.5%	47.3%	9.6%	14.5%	6.1%
Birth to Three Service Coordination	36.7%	38.9%	7.1%	12.2%	5.1%
Board of Services for the Blind	6.4%	25.7%	30.2%	32.5%.	5.1%
Children with Special Health Care Needs	10.3%	31.2%	24.4%	28.9%	5.1%
Commission on the Deaf and Hearing Impaired	4.5%	26%	30.2%	33.4%	5.8%
Department of Income Maintenance (Dept. of Social Services)	21.5%	40.5%	14.1%	18.6%	5.1%
Department of Mental Retardation	19.6%	47.9%	10.3%	17%	5.1%
Department of Children and Families	48.6%	37%	3.2%	6.1%	5.1%

TABLE 7 (continued)
Physicians' Knowledge of Public Service Programs

	Well Understood	Somewhat Understood	Not Understood	Need More Information	Missing
Early Periodic Screening, Diagnosis and Treatment	26.4%	38.3%	12.9%	13.6%	5.5%
Healthy Start	24.8%	37%	16.4%	16.7%	5.1%
Medicaid	39.9%	43.4%	4.2%	7.1%	5.5%
Special Education	25.1%	43.1%	10.9%	15.1%	5.8%
Supplemental Social Security (SSI)	13.2%	37.6%	24.8%	18.6%	5.8%
Women, Infants and Children (WIC)	55.9%	31.5%	3.5%	3.4%	5.1%

TABLE 8
Preferred Training Method

	Mean	SD
BROCHURES / INFORMATION PACKETS(N=247)	2.50	2.35
MINI FELLOWSHIP / POST GRADUATE WORK (N=237)	6.05	2.05
PERSONAL MEETING IN DOCTOR'S OFFICE (N=237)	5.39	1.89
EVENING MEETINGS(N=235)	5.25	1.46
GRAND ROUNDS (N=237)	3.01	1.70
SPECIAL SEMINARS (N=238)	3.58	1.52
INFORMATIONAL PHONE CALL (N=233)	4.68	1.78
OTHER (N=175)	4.70	2.62

This question was rated on a Scale of 1(most preferred) to 8 (least preferred). Therefore, the lower the number, the more preferred the format.

List of Figures

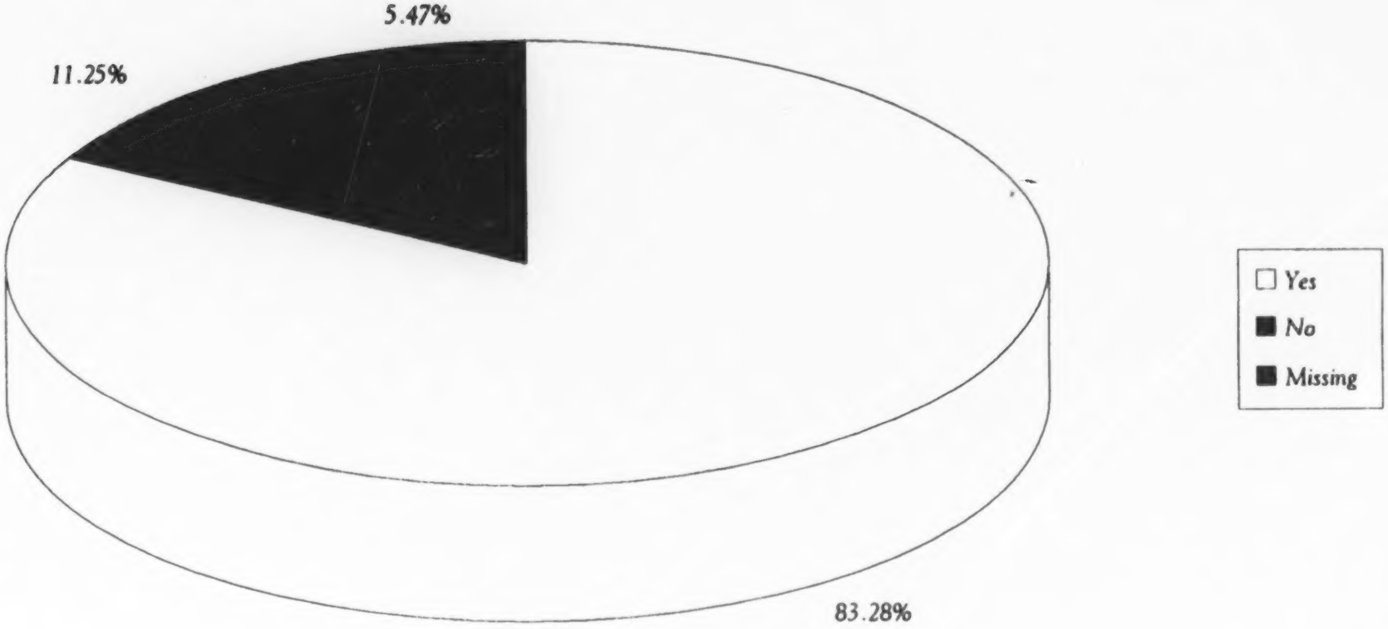

Figure 1. Certified in Pediatrics

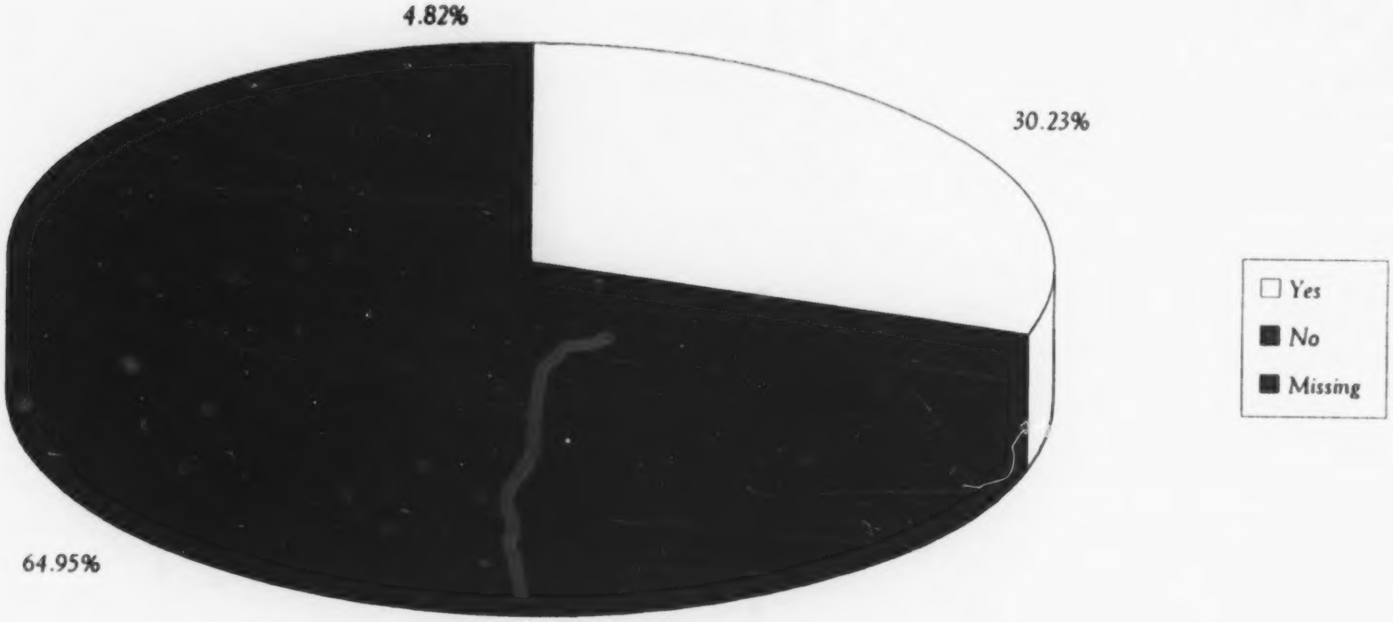

Figure 2. Board Eligible

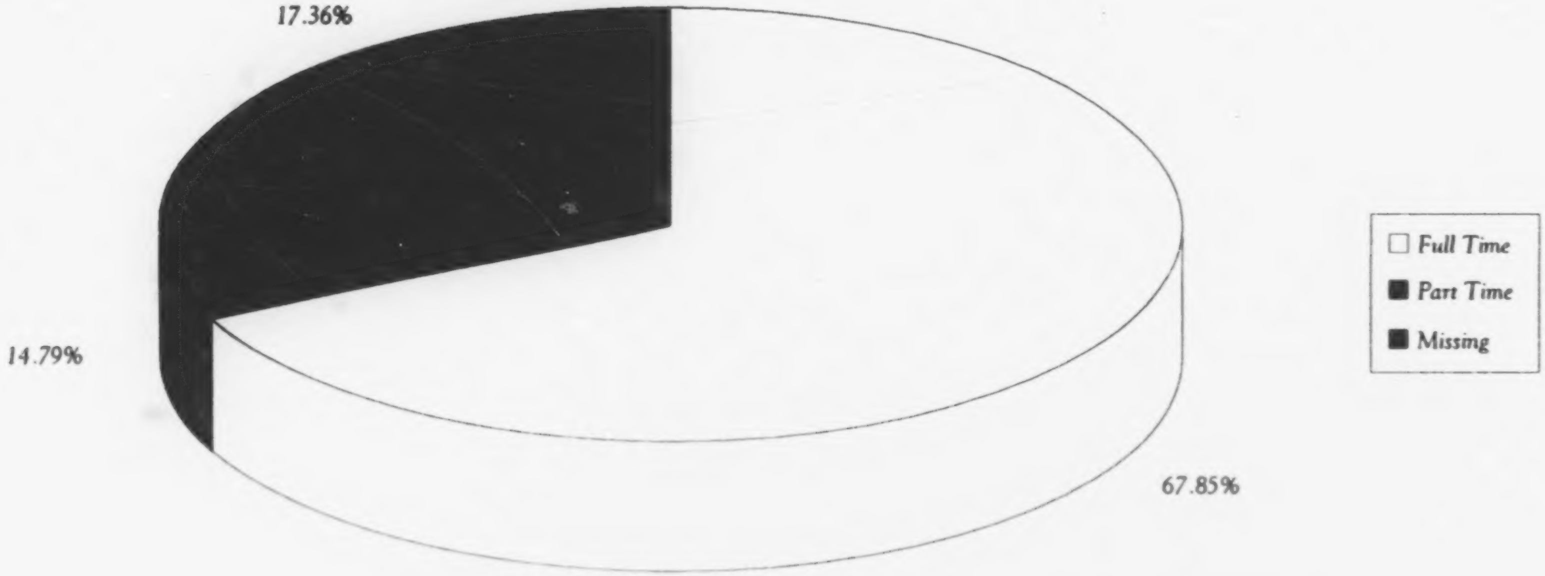

Figure 3. Type of Practice

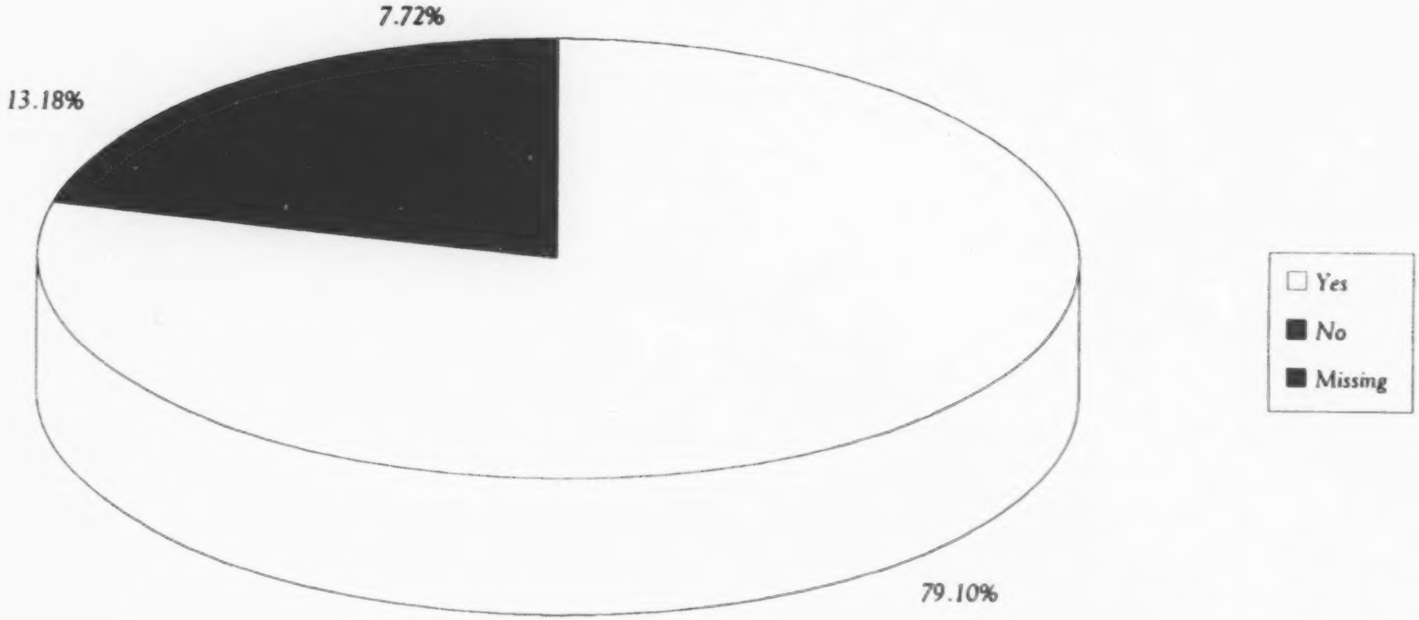

Figure 4. Accepts Medicaid

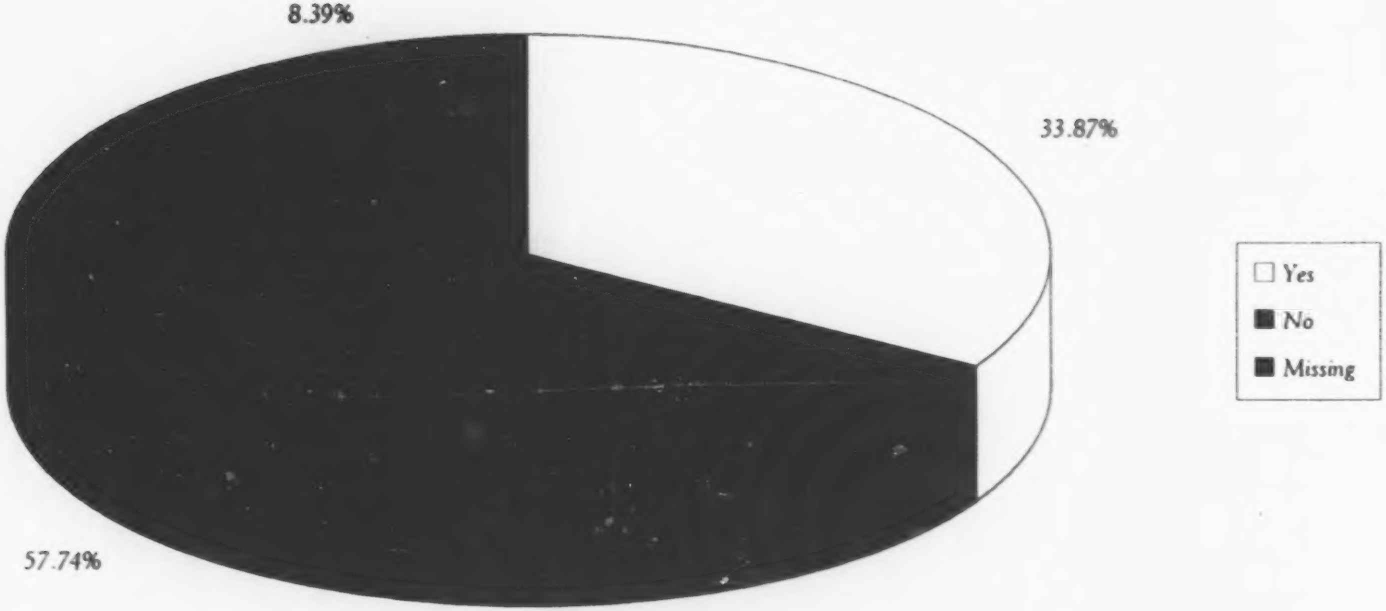

Figure 5. Completes EPSDT

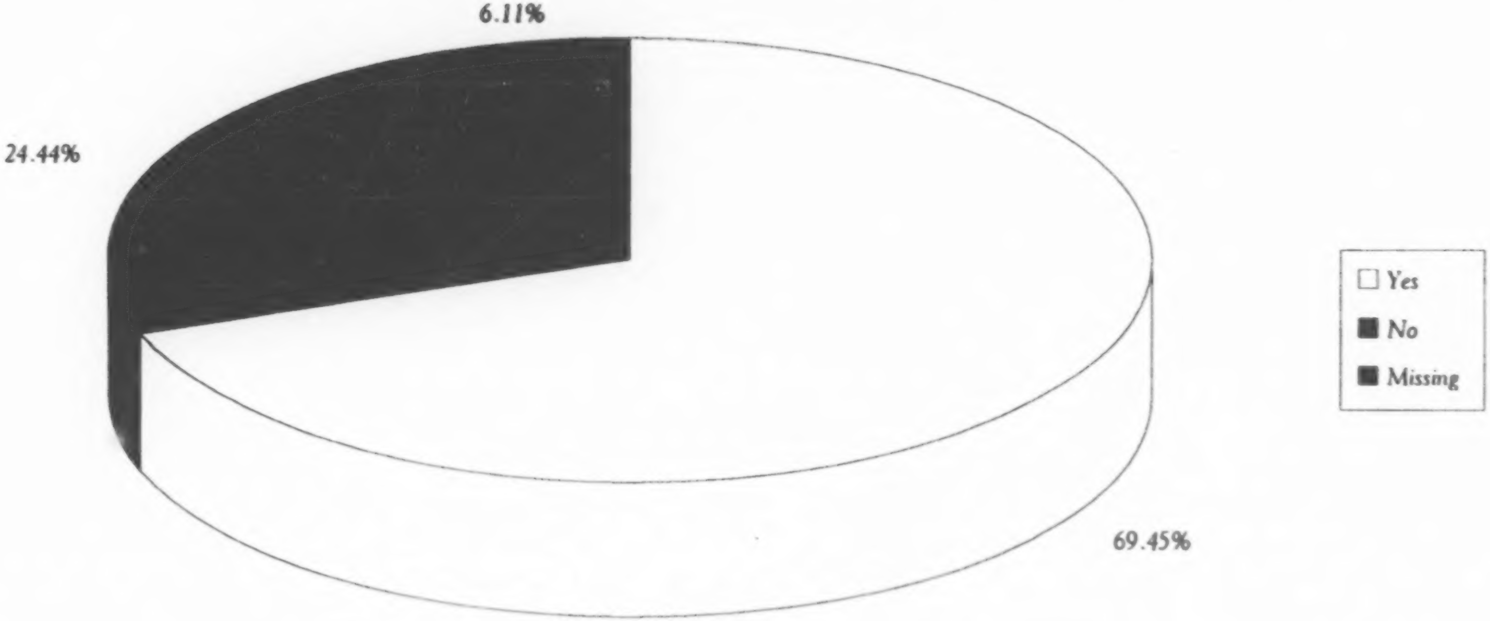

Figure 6. Coordinates Services for Children

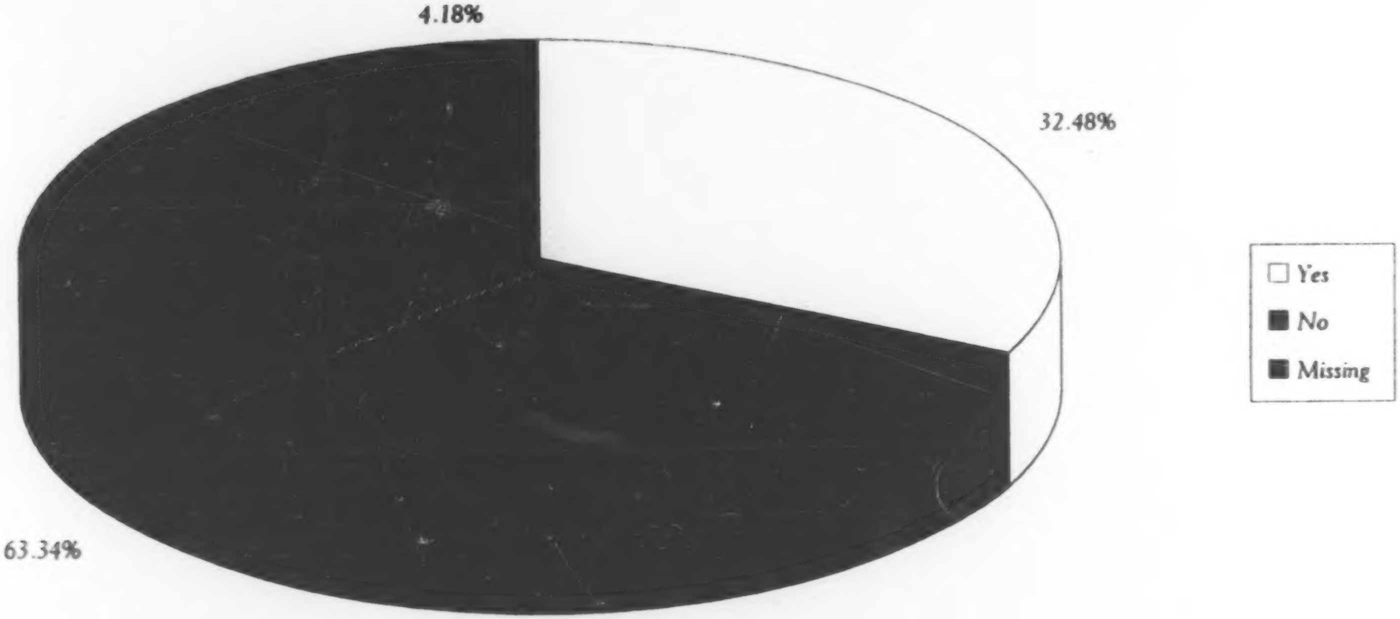

Figure 7. Participated in the development of an Individualized Education Plan (IEP)

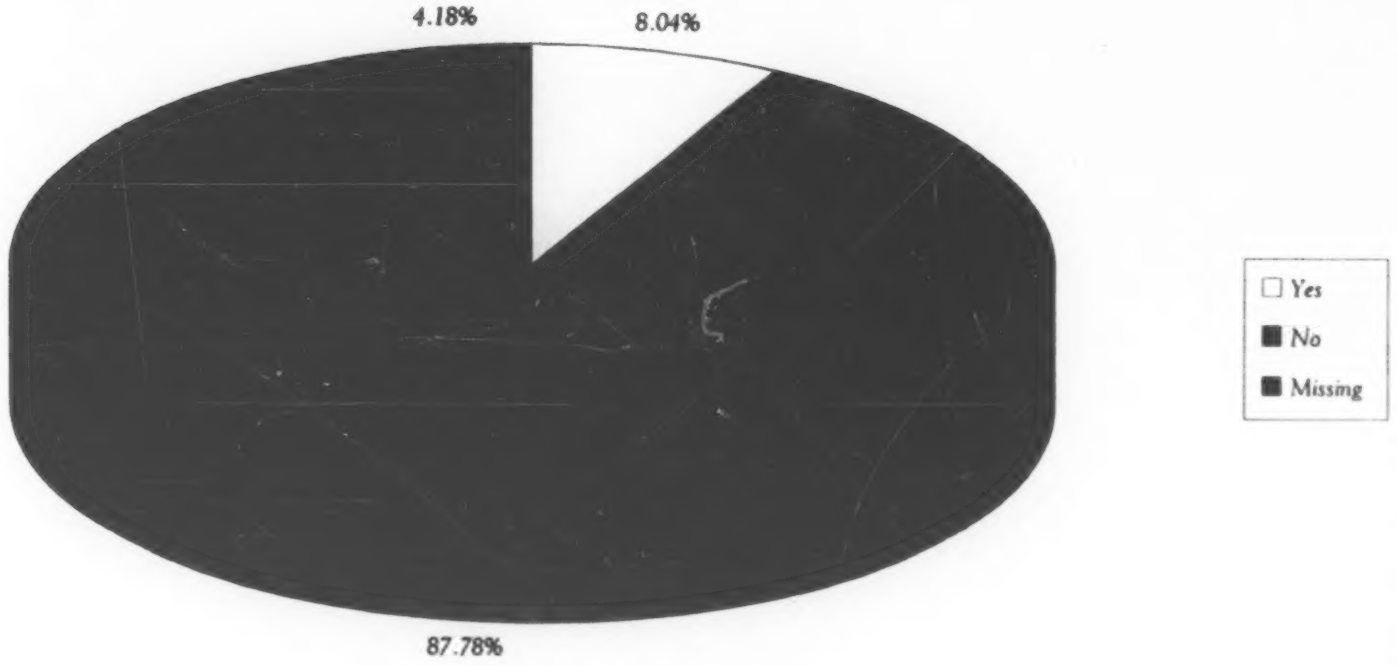

Figure 8. Participated in the development of an Individualized Family Service Plan (IFSP)

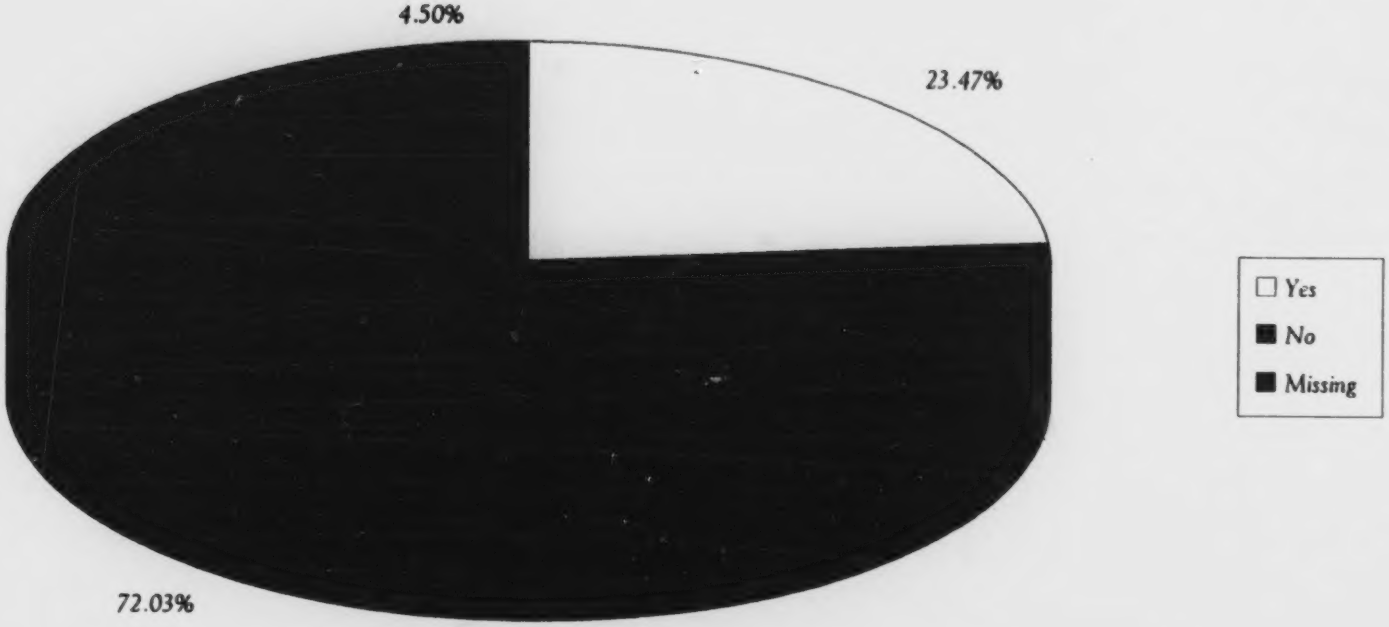

Figure 9. Heard of Part H of IDEA

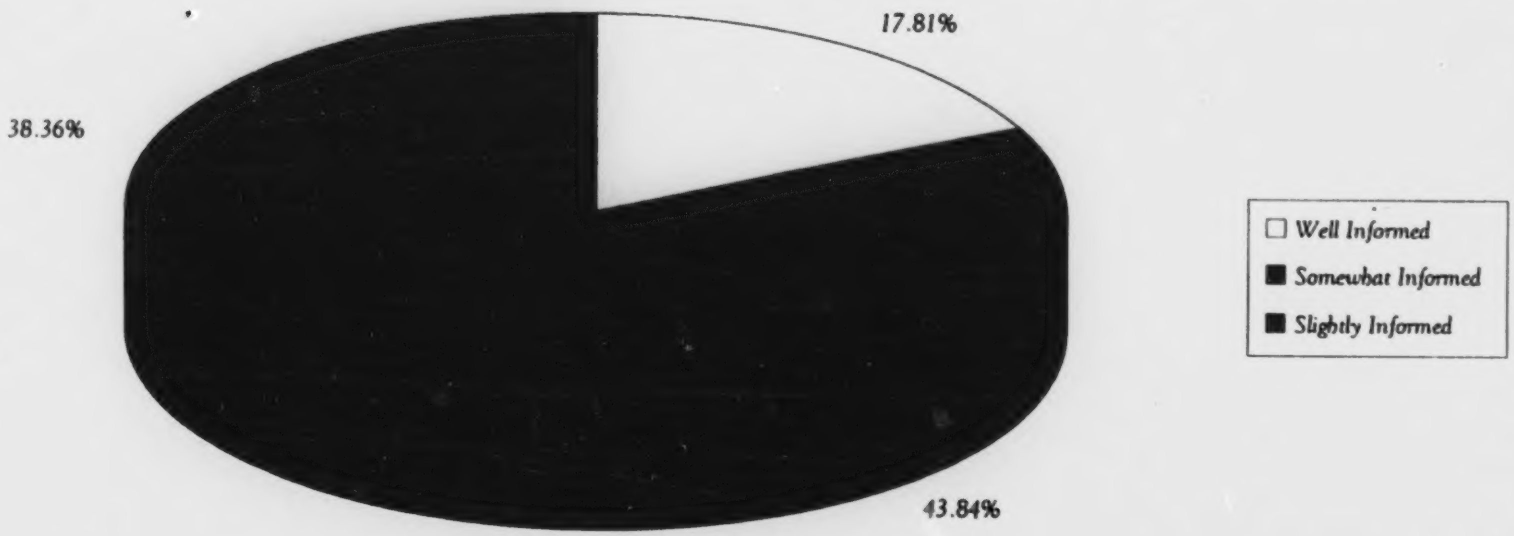

Figure 10. Of those who have heard of Part H, knowledge of this law

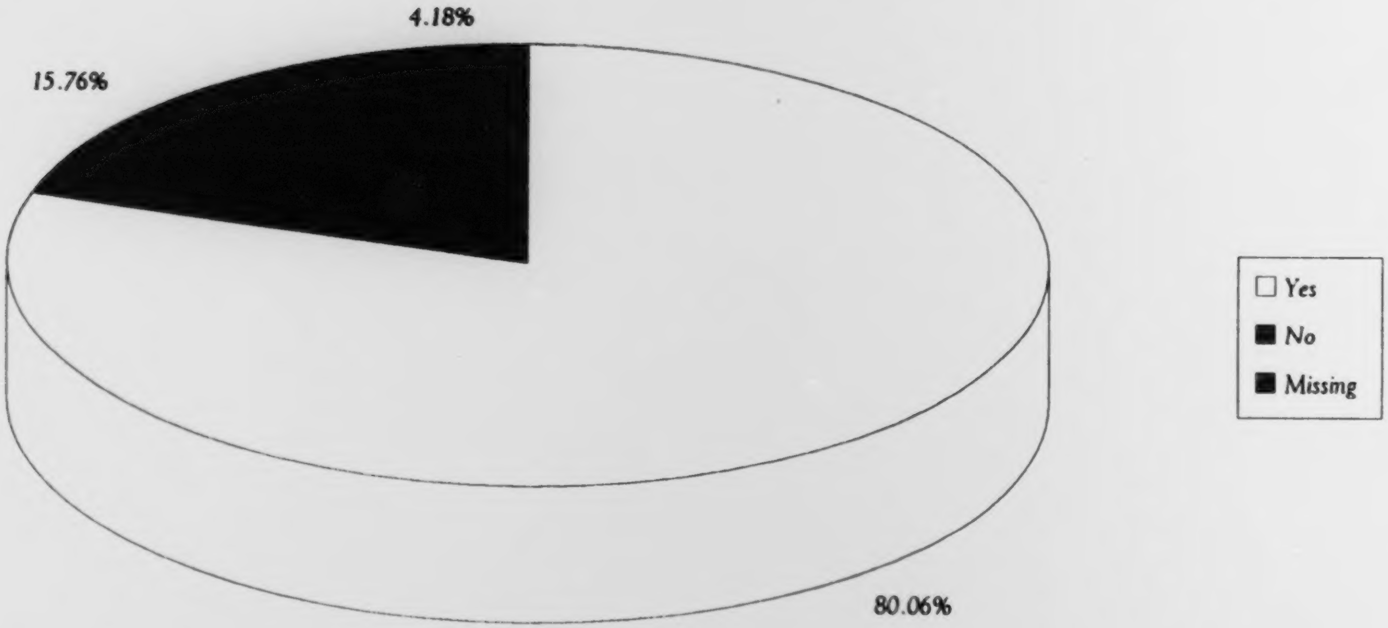

Figure 11. Heard of ADA

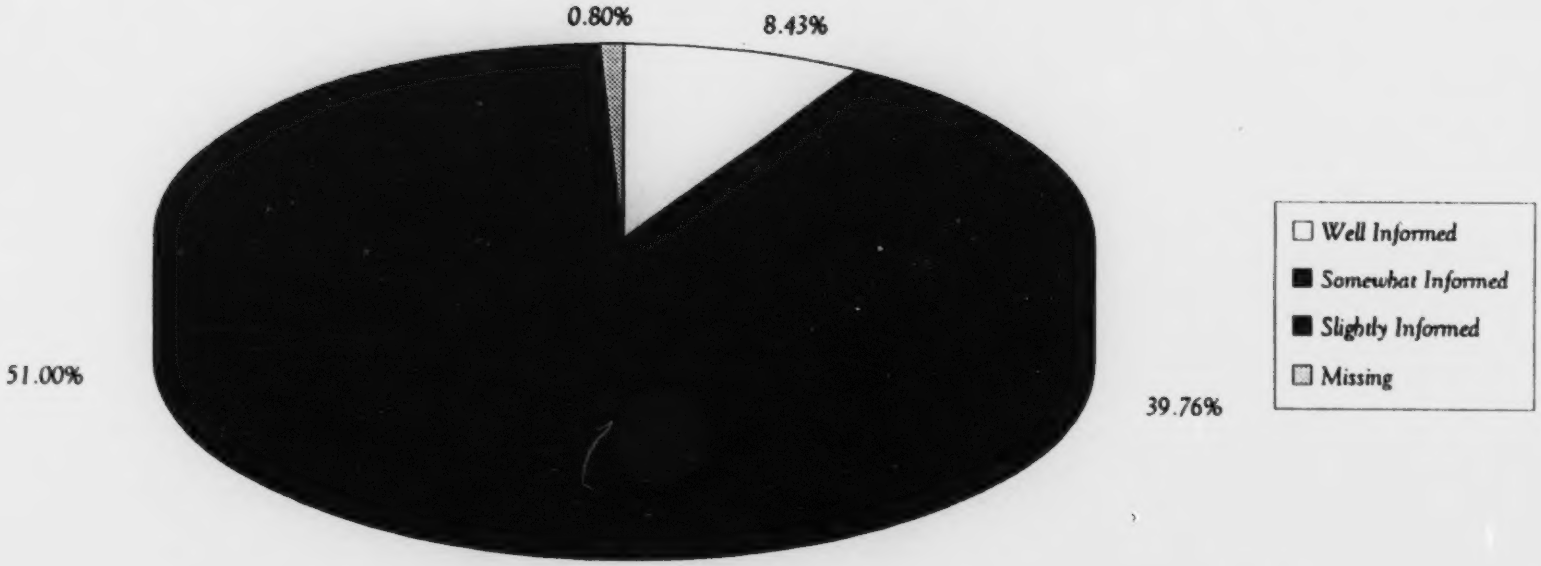

Figure 12. Of those who have heard of ADA, knowledge of this law

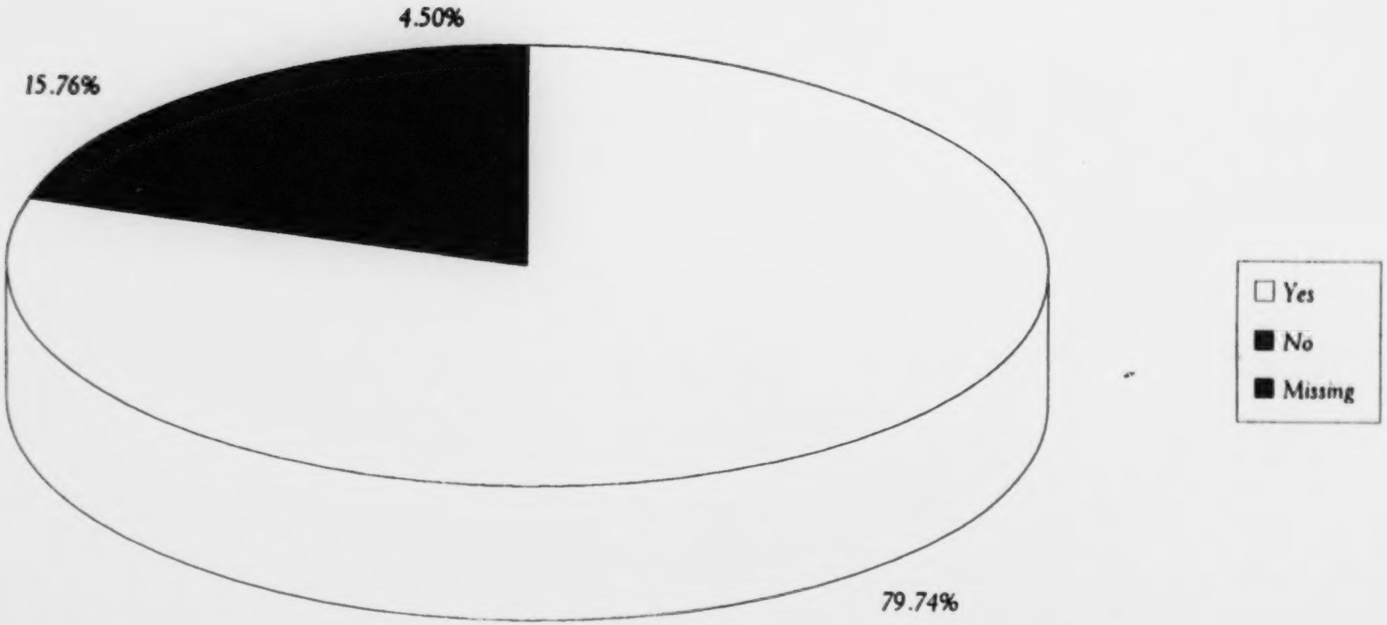

Figure 13. Learn more about any subject under Part H of IDEA

Appendix A

Department of Pediatrics
University of Connecticut School of Medicine

Background

What year did you complete medical school? __________ What year did you complete your residency? __________

What type of practice do you have? ☐ Full Time ☐ Part Time

What is your primary type of practice?
☐ Solo Private Practice ☐ Group Private Practice
☐ Hospital Based Practice ☐ Managed Care Practice
☐ Academic Appointment Yale ☐ Academic Appointment UCONN
☐ Academic Appointment Other
☐ Non Hospital Based Government Employee (e.g. Health Dept.)

What percentage of time do you spend in clinical practice? ____________%

Are you: Board Eligible in Pediatrics? ☐ Yes ☐ No Certified in Pediatrics? ☐ Yes ☐ No

Do you accept patients who are on Medicaid in your practice? ☐ Yes ☐ No

If yes to the above question, do you complete EPSDT check ups? ☐ Yes ☐ No

Children with Disabilities

Did your medical school training include specific curriculum on children with disabilities? ☐ Yes ☐ No

Did your pediatric residency include specific training on children with disabilities? ☐ Yes ☐ No

Do you coordinate services for children in your practice who receive special education or early intervention services? ☐ Yes ☐ No

Have you ever directly participated in the development on an Individualized Education Plan (IEP) for a child in your practice? ☐ Yes ☐ No

Have you heard of Part H of the Individuals with Disabilities Education Act (IDEA) ☐ Yes ☐ No

If you answered yes to the previous question, how would you rate your knowledge of this law?

☐ *Well Informed.* I feel comfortable advising the parents of my patients on the services provided by this law.

☐ *Somewhat Informed.* I know about the law and I can give the parents of my patients a basic overview of the services provided by this law.

☐ *Slightly Informed.* I've heard about the law but I would not feel comfortable advising the parents of my patients on the services provided by this law.

Have you directly participated in development of an Individual Family Service Plan (IFSP) for a child in your practice? ☐ Yes ☐ No

Have you heard of Americans with Disabilities Education Act (ADA) ☐ Yes ☐ No

If you answered yes to the previous question, how would you rate your knowledge of this law?

☐ *Well Informed.* I feel comfortable advising the parents of my patients about their rights under this law.

☐ *Somewhat Informed.* I know about the law and I can give the parents of my patients a basic overview about the rights under this law.

☐ *Slightly Informed.* I've heard about the law but I would not feel comfortable advising the parents of my patients about their rights under this law.

How would you rate your understanding of the following public programs and their relationship to the care of children with disabilities?

	Well Understood	Somewhat Understood	Not Understood	Need More Information
Aid to Families with Dependent Children	☐	☐	☐	☐
Birth to Three Service Coordination Center	☐	☐	☐	☐
Board of Services for the Blind	☐	☐	☐	☐
Children with Special Health Care Needs	☐	☐	☐	☐
Commission on the Deaf and Hearing Impaired	☐	☐	☐	☐
Department of Income Maintenance	☐	☐	☐	☐
Department of Mental Retardation (DMR)	☐	☐	☐	☐
Department of Children and Youth Services	☐	☐	☐	☐
Early Periodic Screening, Diagnosis and Treatment	☐	☐	☐	☐
Healthy Start	☐	☐	☐	☐
Medicaid	☐	☐	☐	☐
Special Education (Local Education Agency)	☐	☐	☐	☐
Supplemental Security Income (SSI)	☐	☐	☐	☐
Women, Infants, and Children (WIC)	☐	☐	☐	☐

Would you be interested in learning more about any subject pertaining to young children with disabilities and services under Part H of IDEA? ☐Yes ☐No

If you are interested in learning more, what arrangement would work best for you? Please prioritize, 1=Most Preferred, 8=Least Preferred format.

☐ Brochures/Informational Packet
☐ Mini Fellowships/Post Graduate work
☐ Personal Meeting at your office
☐ Evening Meetings
☐ Grand Rounds
☐ Special Seminars
☐ Informational Phone Call
☐ Other____________________

If you are interested in receiving information about the results of this survey, or any of the topics mentioned, please fill out the information below.

Name______________________________

Address______________________________

City ______________ State______________ Zip________

Phone __________

Are there specific topics you want more information about (please list).____________________

Once again, thank you for your time.

When completed, fasten by taping or stapling, place stamp where indicated and return to address listed on back cover.

APPENDIX E

Introduction

One of the goals of The Physicians Training grant is to provide practicing physicians with training on early intervention and special education systems for children with disabilities and their families. In addition to grand rounds presentations at hospitals across the state of Connecticut, a series of special interest seminars was developed entitled **Current Issues in the Delivery of Services to Children with Developmental Disabilities and Their Families.**

The seminar series was designed to facilitate collaboration among healthcare providers and interested colleagues in Connecticut. The primary intent was for professionals from the future Connecticut Children's Medical Center (comprised of the Departments of Pediatrics from the University of Connecticut Health Center, Hartford Hospital, and Newington Children's Hospital) to work toward creating a shared vision of practices for children with disabilities and special healthcare needs and their families. Parents, early intervention service providers, professionals from related agencies, and others were also welcomed.

An introductory letter and seminar flier (Appendix A) were mailed to a list of approximately 500 professionals. Announcements were also posted in the weekly newsletter at each hospital and at St. Francis Hospital and Medical Center.

All four seminars were held at the Hamilton Heights Conference Center in West Hartford, one Friday per month from 3:00 p.m. to 5:00 p.m. Refreshments were provided.

The number of registrants and number of attendees for each seminar is summarized in the following table. Appendix B contains a list of participants for each seminar.

	Session A	Session B	Session C	Session D	Total
Registered	34	62	61	60	217 (91)*
Attended	26	38	26	24	114

* This number represents the actual number of individuals who registered for the seminars. Many of the participants registered for and attended more than one seminar.

Of the total number of registered participants (91):

- 28.6% were doctors
- 23.1% were educators
- 13.1% were nurses/dietitians
- 17.6% were practitioners from other agencies such as the Department of Mental Retardation, The Family Center, the Department of Health and Addiction Services, and the fields of psychology and social work
- 17.6% were unknown in terms of their professional titles

A summary of the content covered by each presenter follows. At the conclusion of each seminar, participants completed a Consumer Satisfaction Survey. Appendix C contains the statistical data from the Consumer Satisfaction Surveys. Participant written comments are contained in Appendix E.

Session A

Date: September 9, 1994

Speaker: Michael J. Guralnick, Ph.D.
Director, Child Development and Mental Retardation Center, University of Washington, Seattle, Washington

Topic: Research and Practice in Mental Retardation

Summary

Dr. Guralnick presented research data on the components of effective early intervention programs. He discussed the effectiveness of broad based and comprehensive intervention programs that incorporate parent involvement and parent change as essential components. Parent mediated intervention; infant stimulation techniques; exploration of parent perceptions, fears, and expectations; and facilitation of daily care routines were reviewed.

The speaker discussed implementation of a curriculum that must begin in the neonatal intensive care unit and be carried over to the home environment. The goals of this curriculum emphasize parent/child interaction; transactions that involve sensitivity, synchrony, and reciprocity; and methods for building parent confidence, satisfaction, and competence. A discussion of ways to enhance social support networks and parent-professional partnerships also was included.

Dr. Guralnick briefly discussed his thoughts about intensity of services. Intensity or frequency of services is not the sole factor in determining effectiveness of a program. Rather, effectiveness of service provision with any child is impacted by comprehensiveness of programming, severity of the disability, and level of family functioning, as well as the intensity and frequency of services.

The remainder of Dr. Gurlanick's presentation focused on social competence and peer relationships. Research shows that social competence fosters the development of communicative and cognitive skills, as well as social acceptance and integration. Peer-related social competence can be assessed with the Social Participation Scale, the Individual Social Behavior Scale, and various communicative measures. Assessments need to examine the impact of language, cognition, affect, and motor skills on the domains of social competence. These domains include: a) shared understanding, b) emotional regulation, c) social-cognitive processes, and d) higher order processes and executive functions. Studies reveal that children with disabilities need systematic assessment and preventive intervention programs in peer-related social competence, as well as experiences in integrated settings with typically developing peers.

Consumer Satisfaction Results

At the completion of the session with Dr. Guralnick, participants rated their satisfaction with the relevance of the content, the way the presenter presented, and the convenience and comfort of time and location. With the exception of convenience of day and time (3.62), the average scores for this session suggest these participants were satisfied with scores of 4.00 or better (4.0=mildly agree, 5.0=strongly agree). See Appendix D for data summaries and Appendix E for participant written comments.

Session B

Date: October 21, 1994

Speaker: Phil Strain, Ph.D.
Assistant Executive Director, St. Peter's Child Development Centers, Pittsburgh, PA

Topic: Research and Practice in Autism and Pervasive Developmental Disorder

Summary

Dr. Strain opened his presentation with a discussion of the need to evaluate whether the ecology or environment of a classroom is set up to promote engagement and interaction among children. He cited studies that support planned and regular opportunities for children with Autism and Pervasive Developmental Disorders (PDD) to interact with typically developing peers.

Dr. Strain believes that children with Autism and PDD use atypical behaviors as a means of communication intended to have others not interact with them. He discussed how the atypical behaviors may be reinforced by others (often unknowingly) by their withdrawal from the interaction. Thus, typically developing children must be taught to be persistent in their social approaches even in the face of the atypical behaviors. By formally teaching other children to sustain the interaction, the atypical behavior no longer serves its purpose.

The speaker stated that there can be no therapeutic effect or outcome without careful planning, structuring, and intervention. His view is that outcomes for children who have Autism or PDD are not solely due to modeling, as modeling implies imitative intent. Rather, the concept of "behavioral contagion" suggests that children have sensitivity and a "tuned-in-ness" that allows them to pick up the positive or negative behaviors of other children.

Dr. Strain then discussed the need for a planned, executed, and evaluated teaching program. In order to assure effectiveness, the evaluation of teaching strategies must occur on a daily basis. Programs need to be fluid and constantly changing. He stated that intensity of services should not be measured by number of hours, as research demonstrates this is not always a relevant variable. The intensity of the intervention must be based on the individual needs of the child and the family. No one intervention plan will meet the needs of all children. Instead of focusing on number of hours, the emphasis should be on outcomes for the child and the family.

A participant asked Dr. Strain to comment on Lovaas training techniques. Dr. Strain commented briefly that Lovaas involves one-on-one teaching and no group experiences. He commented that some of the interventions are restrictive and punitive. Some of the other behavioral techniques, such as distributed trials, masked trials, and discrete trials, can be applied in other intervention models.

Finally, Dr. Strain commented that challenging or difficult behaviors must be addressed with positive, proactive strategies. Professionals and parents need to pick their battles carefully with children. Rather than trying to suppress negative or undesirable behaviors, the focus should be on enhancing positive or adaptive behaviors. Focusing on negative behaviors takes a toll on the family and services providers because the identified problem becomes the goal of intervention, rather than the needs of the whole child.

Consumer Satisfaction Results

Consumer satisfaction surveys were mailed to all participants of this seminar. A bibliography of Dr. Strain's work was also enclosed (Appendix F). Of 38 surveys mailed, 6 were returned. The data suggests that participants were less satisfied with the content, organization, and relevance of this seminar as compared with other seminars. Day, time, and opportunity for discussion were also less than satisfactory. In all of the areas mentioned above, scores were below 3.88 (3.0=neutral, 4.0=mildly agree). Participants were more satisfied with the knowledge of the presenter (4.75) and the comfort of the environment (4.63). See Appendix D for data summaries and Appendix E for participant written comments.

Session C

Date: November 18, 1994

Speaker: W. Carl Cooley, MD
Assistant Professor of Pediatrics, Dartmouth Medical School and Associate Director, Dartmouth Center for Genetics and Child Development/UAP, Dartmouth. NH

Topic: Systems Change in Pediatrics: Family Centered Care for Children with Disabilities and Chronic Illness

Summary

Dr. Cooley opened his presentation by discussing the impact of the increasing number of medically fragile infants, who are now surviving and entering the community with needs for healthcare and education. He commented on the fragmented and highly specialized healthcare services that are now prominent in both medical student training and in physician practices. There is currently no role model for the primary care provider who is treating children with chronic illnesses and disabilities.

The speaker discussed how having a child with disabilities or a chronic illness shakes the foundation and culture of family life and how the family has needs that go beyond the needs of the child. Dr. Cooley stated that there is clear evidence that family support enhances outcomes for the child, as well as the family.

Studies of the beliefs of primary care physician were cited. Research indicates that many primary care physicians believe that they do not have the knowledge, time, or clear role definitions required to treat children with chronic illnesses or disabilities. Results of these studies dictate what kinds of support physicians need, including: a) education and training; b) systems change, office organization, and reimbursement changes; and c) enhanced role definition and communication among healthcare providers. The relationship between parents and primary care providers is often based on hidden or erroneous assumptions about who is responsible for doing what in terms of caring for the child. As an example, Dr. Cooley described a child with epilepsy whose neurologist provides care for the seizures in isolation, while the primary care physician and school nurse are left out of the loop. Dr. Cooley discussed the need for explicit communication systems among parents, primary care physicians, specialists, other healthcare providers, and other service providers.

Dr. Cooley introduced two projects that address the need for systems change within physician's office practices: The Guiding Appropriate Pediatric Services Project (GAPS), and The Office Partners Project (part of the New Hampshire Partners in Health Project). The focus of the remainder of Dr. Cooley's presentation was on The Office Partners Project.

Specific components of this project were outlined. The goal of the Office Partners Project is to assist primary care physicians in working with or treating children with chronic conditions within the office setting. A system of Chronic Condition Management (CCM) techniques has been designed, which entails an enhanced set of primary care services that go beyond well child, preventive, and acute care services. CCM makes available to these parents enhanced resources and a simplified system for utilization of services.

An Office Partners Toolbox was developed to provide specific tools and materials to the entire office staff (including the physicians) within a primary care setting. These tools include such things as, color coded reminders and identifiers, parent/child educational materials, a parent notebook, efficient resource guides and flow sheets, care guidelines, and a priority or "frequent flier" list of patients who require CCM.

Dr. Cooley discussed implications for training medical doctors. In medical school and in their residency, doctors need to learn about families, family support, patient education, promoting self care, and the impact of chronic conditions on school performance. Physicians in training also need exposure to community-based resources and supports.

Participants initiated a discussion of the implications for reimbursement of CCM in terms of managed care, capitation, and the "adverse risk magnet". Dr. Cooley offered thoughts about options such as enhanced capitation and Preferred Provider Organizations specifically designed for children with special healthcare needs.

CCM requires that a care coordinator or care liaison be appointed within the office. Often a nurse can perform this role.

It is recognized that specialty care still is required in many instances. The Office Partners Project attempts to support primary care physicians in co-managing care with the specialist within a multidisciplinary team format. In fact, the new AAP Residency Review Guidelines require this kind of experience.

Consumer Satisfaction Results

Consumer satisfaction data suggests that these participants were satisfied with the content, the presenter's ability to present, and the convenience and comfort of the seminar location with average scores of 4.17 or higher (4.0=mildly agree, 5.0=strongly agree). Participants were less satisfied with the relevance of the information to their work situation (3.72, 3.0=neutral), and the day and time of the seminar (3.81). Dr. Cooley made handouts of these projects available to the participants (Appendix F). See Appendix D for data summaries and Appendix E for participant written comments.

Session D

Date: December 16, 1994

Speaker: Carl Dunst, Ph.D.
Senior Research Scientist and Professor of Psychiatry,
Allegheny-Singer Research Institute, Pittsburgh, PA

Topic: Research and Practice: Supporting and Strengthening Families

Summary

Dr. Dunst opened his presentation with a discussion about the need to view social support for families as a form of intervention, particularly because parents of children with disabilities experience higher levels of stress and distress. The question he put forth was "What is the relationship between social support and health outcomes?" Dr. Dunst believes that the parents' psychological well-being would not be as negatively effected if supports were present to mediate the birth of a child with a disability.

Dr. Dunst described an ecological perspective whereby the behavior and development of the child are influenced by events that the child does not necessarily experience directly. He pointed out that parental stress may come from things other than the disability itself, as well as events that are directly or indirectly linked to the disability. Stress in other parts of the parents lives, such as the work place or the family of origin, may also influence their ability to carry out their parenting responsibilities. Dealing with professionals who are providing care for their child may also be a source of stress. Dr. Dunst feels that often professionals tend to only attribute problems in families to the disability, rather than looking at other possible sources of stress.

Barriers to supporting and strengthening the family include conducting team meetings without the family present, focusing on the child's disability rather than his or her competencies, and entering into the evaluation process. Dr. Dunst advocates for a family friendly and positive focus to help relieve some of the stress.

Discrepancies between the family's knowledge of and perception about their child's disability, and how the child is actually functioning can also lead to stress. The wider the discrepancy between the parent's expectations and the outcomes of intervention, the higher the stress level.

Dr. Dunst outlined different types of support for families, including:

- relational ties - spouse, family of origin, community or religious organizations
- constitutional support - a person's own perception of the need for support, without which efforts toward support may not be received
- functional support systems - child care, financial resources, informational resources

Support satisfaction must be formally examined. If a person is not satisfied, he or she will not benefit from the support that is offered. Help-giving practices and the characteristics of help-givers are directly related to a person's sense of control. There is a continuum of program models moving from professionally centered, to family allied, to family focused, and finally to family centered. The relationship between help-giving practices and the program model needs to be looked at. Effective help-giving is based primarily on how the help is provided within the structure or context of the program. Help-giving characteristics and program characteristics need to allow parents a feeling of control in terms of obtaining what they need for their child.

A discussion about the Diagnostic Statistical Manual (DSM) followed. The DSM was viewed as being based on a disease model, being shaped by insurance and reimbursement guidelines, and being a professionally centered document.

Dr. Dunst closed by stating that we as professionals can never completely take a parent's perspective. Thus we need families to shape training, policy, effective practices, and program design.

Consumer Satisfaction Results

Consumer satisfaction data from this seminar suggest that again participants were satisfied with all aspects of content, delivery, and presenter knowledge with average scores at 4.05 or better (4.0=mildly agree, 5.0=strongly agree). Materials and day and time of the seminar were viewed with less satisfaction (3.53, and 3.84 respectively, 3.0=neutral). See Appendix D for data summaries and Appendix E for participant written comments.

Summary

Overall, participants expressed satisfaction with the presenters and the content of their presentations. Participants also indicated satisfaction with the opportunity for discussion and the knowledge of the presenters. While the environment and location were satisfactory, the day and time were not.

In their written comments (Appendix E) participants indicated the need for more information regarding state systems of early intervention and education, funding sources, specific practices for children with certain types of disabilities, and working within the managed care system.

Results of Consumer Satisfaction - Special Interest Seminar Series: Current Issues in the Delivery of Services to Children with Developmental Disabilities and Their Families

	Mean Score for Each Question (Standard Deviation)				
	A	B	C	D	ALL
1. Objectives of the seminar were met.	4.14 (1.24)	3.63 (1.19)	4.17 (0.86)	4.16 (1.01)	4.09 (1.06)
2. The materials (handouts, slides, overheads) were relevant to the content.	4.36 (1.18)	3.50 (1.07)	4.50 (0.86)	3.84 (1.21)	4.15 (1.13)
3. Time was well organized.	4.14 (1.13)	3.38 (1.51)	4.44 (0.78)	4.05 (1.13)	4.10 (1.12)
4. The information is relevant and can be applied to my work situation.	4.14 (1.15)	3.88 (1.13)	3.72 (1.32)	4.05 (1.18)	3.97 (1.19)
5. The presenter was well prepared and organized.	4.59 (1.05)	3.38 (1.30)	4.61 (0.70)	4.33 (1.08)	4.38 (1.06)
6. The presenter was knowledgeable in the subject.	4.64 (1.18)	4.75 (0.46)	4.83 (0.51)	4.68 (0.95)	4.72 (0.88)
7. The environment was comfortable.	4.23 (1.23)	4.63 (0.52)	4.89 (0.32)	4.42 (1.02)	4.51 (0.94)
8. The location of the seminar was convenient for me.	4.00 (1.30)	3.63 (1.51)	4.63 (0.72)	4.05 (0.85)	4.13 (1.11)
9. The day and time of the seminar were convenient for me.	3.62 (1.24)	3.38 (1.30)	3.81 (1.47)	3.53 (1.26)	3.61 (1.29)
10. There was enough opportunity for questions and discussion.	4.43 (1.21)	3.50 (1.41)	4.94 (0.25)	4.58 (0.96)	4.48 (1.07)

Seminar Series Speakers:

A	9/9/94	Michael J. Guralnick, Ph.D.
B	10/21/94	Phil Strain, Ph.D.
C	11/18/94	W. Carl Cooley, MD
D	12/16/94	Carl Dunst, Ph.D.

Mean Scores are defined by the following scale:

1 indicates that you strongly disagree with the statement,
2 indicates that you mildly disagree with the statement,
3 indicates that you are neutral about the statement,
4 indicates that you mildly agree with the statement,
5 indicates that you strongly agree with the statement.

Participant Comments from September 9, 1994

What did you find most helpful about this seminar?

Presentation of research data was a perfect framework for a beginning understanding of social competence approach. This approach is quite obviously where we need to be heading for the future in early intervention service provision.

Information on latest research and the speaker's own work.

Emphasis on social domain of development.

Application to practical clinical situations.

Discussion.

Presenter's ability to relate to "real-life" situations.

Contacts with others in the field.

Discussion.

Content and idea stimulation
Interaction with community people.

Specific studies done and results.

What did you find least helpful about this seminar?

All helpful.

Most of presentation and published statistics were common knowledge and added very little to understanding the development of programs to utilize early intervention.

Nothing.

What ideas do you have for future seminar topics?

State systems of education, funding services - periodic updates.

Less academic and more practical. How do you actually implement these programs/ideas - more "nuts and bolts".

More about Cerebral Palsy.

Please provide any other comments that may benefit us.

Thank you for the knowledge! Wonderful.

This meeting served as an introduction to the seminar.
Please start on time.

Keep up the good work. Get more publicity. Try to get parent to invite their doctor, etc.

Great!

To know about services that are available.

I have been at 3 meetings with Michael in the past 2 days - I didn't realize before this afternoon what a treasure he is to us. His knowledge and skill in presenting are excellent. I am looking forward to the future seminars.

Participant Comments from October 21, 1994

What did you find most helpful about this seminar?

Excellent and informative.

I was encouraged re: progress in the field.

This topic was very important in Connecticut which has little to offer young autistic children. We need to work on developing the most beneficial programming for these children and help for their parents.

The topic itself - information on Autism is very relevant to many professionals and new information is always needed.

The strong message that mainstreaming was extremely effective with autistic children.

Content.

What did you find least helpful about this seminar?

His flip attitude was distracting, I realize he was tired.

The speaker was obviously tired and he was often difficult to follow. His research was important, however.

Presenter was not very organized and did not disseminate relevant material.

The speaker digressed too much and thereby weakened the content of his presentation. I believe he has a lot of knowledge which was not imparted at this meeting.

Speaker was tired and distracted.

Speaker was pooped and had to leave without enough opportunity for questions and discussions.

What ideas do you have for future seminar topics?

Families in Connecticut are hearing that more hours are better. I'd love information to share with families so that they can see that there are alternatives to "more is better", to educate themselves and have guidance to share. Also, where is programming (for children with Autism) happening in CT or in Massachusetts?

More information on development, treatment, treatment efficacy, prognosis, and types of PDD/Autism.

Please provide any other comments that may benefit us.

Please have future speakers bring a bibliography or a reprint of a major research article for us.

The presenter was obviously very knowledgeable about the subject but was too tired and more interested in letting us know that. Stories were humorous but took up precious time for such a short session.

Participant Comments from November 18, 1994

What did you find most helpful about this seminar?

Sharing of philosophy and intervention approaches.

Applications of strategies to enhance family centered practices.

The question and answer period and overall presentation.

Good review. How to involve Primary Care Physicians in caring for children with chronic conditions.

What did you find least helpful about this seminar?

Environment was too dark.

What ideas do you have for future seminar topics?

Dealing with HMOs.

Please provide any other comments that may benefit us.

Sorry, but this one just didn't pertain much to my work.

Participant Comments from December 16, 1994

What did you find most helpful about this seminar?

The content and research insights provided by the speaker.

Question and answer period.

Application to work experience.

Very relevant to birth to three.

Reaffirm an approach that I know is right even though the CT Part H system operates otherwise and would like to convince us that what we've been doing is wrong.

It validated what I already believe.

The questions asked were precise and relevant.

Effectiveness of family directed model.

Reinforce concept of involving parents and other family members. Social support very important.

What did you find least helpful about this seminar?

Time. Zzzzzzzz.

Would have liked more overheads - but, then, they may appear in his next book.

Furnace operating frequently was loud and distracting.

Delivery was lack luster. Statistical charts somewhat confusing (R =.36?)

What ideas do you have for future seminar topics?

More of the same to rehabilitation centers.

I'd like to hear more from Mr. Dunst.

Time management.

Cost containment in Early Intervention. How to design good programs in cost effective manner - but objective and loaded with data.

Please provide any other comments that may benefit us.

Please ask the speakers to take a short break after an hour - it is late in the day on a Friday and it would be beneficial to move a round, get cup of coffee, etc.

Better descriptions of each conference would be beneficial in choosing which conferences are most applicable to individual practices.

APPENDIX F

TIPS:

Trends for Inclusive Pediatric Services

Family
Alliances
Physician

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University of Connecticut Health Center
Department of Pediatrics
Division of Child and Family Studies

TIPS: Trends for Inclusive Pediatric Services was developed by:

The Physicians Training Project

Project Director: Mary Beth Bruder, Ph.D.
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TIPS:

Trends for Inclusive Pediatric Services

Physicians and other healthcare providers are often the first people parents speak with when they have concerns about the development of their children. Thus, the healthcare provider is often the critical entry point for families to access information, resources, and services designed to enhance a child's development in all realms. Meeting the needs of children with disabilities or special healthcare needs is a complex process for all involved. It requires highly refined skills in communication, cooperation, coordination, and collaboration. These collaborative efforts must involve parents, other family members, primary care physicians, other healthcare providers, and other service providers in a close partnership. When fully realized, alliances and collaborative efforts enhance the care provided to children and improve the outcomes for children and their families.

Physician training, as well as training in other human services fields, is beginning to incorporate a more comprehensive, coordinated, system-based model of care that defines how services should be provided within the context of the family's needs. The principles of family centered care and cultural competence are key in this approach. Parents should be viewed as the ***experts*** regarding their children, because they are. Their input must be valued as essential for providing appropriate care that recognizes the family's unique role. Parents provide the bulk of direct care, advocacy, and coordination of services for their children. For this reason, parents need to be supported in their natural care giving roles by being fully informed and respected as active decision makers. When parents feel valued and competent, they become more effective in caring for their children. For those who are willing to listen and learn,

> **"... a large part of the answer to the problems of parents and professionals working together lies within each person - in eliminating his or her own insecurities, honing their own skills, raising their self-assuredness, and increasing their self-esteem to such a level that others will say of us, in this day and time, that the only thing that exceeds our competence, our compassion, and our caring is our ability to collaborate."**
>
> **R. B. Darling & M. I. Peter (1994)**

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parents can be excellent teachers, offering healthcare and service providers valuable information about their experiences with and knowledge of their children.

The role of the primary care physician is expanding in many ways. A shift in paradigms is occurring from the purely clinical or biomedical perspective to a model that emphasizes a social systems or biopsychosocial perspective. In 1978 the APA task force indicated the need for physicians to gain skills for:

- providing care to children with biosocial and developmental needs.
- improving interpersonal and professional approaches toward children with disabilities and their families.
- improving and increasing participation on interdisciplinary teams.

Best Practices

- *Family centered*
- *Comprehensive*
- *Coordinated*
- *Collaborative*
- *Community based*
- *Continuous*
- *Culturally competent*

In addition, physicians need to be aware of the variety of problems and risk factors for children, i.e. illness, disease, developmental delays, and behavioral difficulties. Biological and environmental risk factors that may cause developmental delays or disabilities need to be considered as well. Helping family members adjust to and live with their child's difficulties is increasingly part of the continuum of pediatric services along with prevention, health promotion, well child care, acute condition care, treatment, and rehabilitation. Thus, healthcare providers need information about the resources, supports, and services available to families. It is the responsibility of healthcare and service providers to assure that services are coordinated, complimentary, and consistent. A well integrated network of services addressing the total needs of the child and family is essential.

There are a number of barriers to providing effective and comprehensive care to children with disabilities and special healthcare needs and to their families. Services are often fragmented due to a lack of communication and coordination among healthcare and service providers, as well as with the family. Roles, responsibilities, and expectations may not be clearly defined and individual efforts may not be efficiently coordinated or managed.

Several key concepts are associated with best practices in both primary care ***and*** early intervention philosophies and practices. These promote care that is family centered, community based, comprehensive, and collaborative. To this end the **Family-Physicians Alliances Project** is an effort to enhance relationships between parents, physicians, and other healthcare providers. In the spirit of building alliances, **TIPS: Trends for Inclusive Pediatric Services** has been developed. Family members of a child with disabilities or special healthcare needs have been asked to share this booklet with you. Our hope is to encourage these partnerships by offering physicians and other healthcare providers information that will be useful in caring for children and supporting families in family centered, comprehensive, coordinated, and collaborative ways.

Who We Are

The Division of Child and Family Studies, part of the University of Connecticut's Department of Pediatrics, administers numerous state and federal grants. These grants provide funding for research, demonstration, and training projects that offer service, support, resources, and materials to personnel from a variety of agencies and disciplines, as well as to families who have children with disabilities or special health care needs.

The mission of **The Division of Child and Family Studies** is to design, develop, and evaluate family centered, comprehensive, collaborative, and community-based service delivery systems that will enhance the development of infants and children who have disabilities and/or chronic illnesses. In support of this mission, the Division of Child and Family Studies is administering a special projects grant, known as the Physicians Training Project. The purpose of this grant is to provide practicing pediatricians, pediatric residents, and medical students with information regarding their role in Connecticut's early intervention and special education systems.

Objectives

It is our intention that the readers of **TIPS: Trends for Inclusive Pediatric Services** will:

- Gain an understanding of the specific components of laws pertaining to children with disabilities, ages birth to 21, and their families, particularly the Individuals with Disabilities Education Act and its provisions for children ages birth to three.
- Gain awareness of skills required to apply the nine principles of family centered care.
- Increase understanding of the value of cultural competence and skills for working with those who are "culturally different" in the broadest sense of the word.
- Gain skills for providing coordinated care to children with disabilities and special healthcare needs and their families.
- Gain understanding of communication practices that are supportive to families and that help family members identify their concerns, priorities, and resources.
- Gain understanding of the benefits of collaboration and alliance building and the skills to do this effectively.
- Understand the advantages and procedures for referring families to early intervention programs, and the physician's role in providing services to children ages birth to three.
- Gain an awareness of ways to maximize community based resources and support systems for children and families.
- Be able to employ tools that make office procedures more efficient for children with disabilities and special healthcare needs.

Finally, it is hoped that readers of **TIPS** will provide ***comprehensive, coordinated, continuous, collaborative, family centered, community based, and culturally competent*** care to children with disabilities and special healthcare needs and their families.

Feedback

In the pocket inside the back cover of **TIPS**, you will find a large postcard which asks for your feedback about this booklet. We would very much appreciate your completing this evaluation form and returning it to us at your earliest convenience. Your response is important to us as we plan further projects that support families and physicians working together in caring for children with disabilities and special healthcare needs.

TIPS

Laws Pertaining to Children with Disabilities

The **Individuals with Disabilities Education Act** (**IDEA**, P.L. 101-476) guarantees that all children with disabilities, ages birth to 21, have a right to a free, appropriate public education. A description of the five underlying premises of the Individuals with Disabilities Education Act (IDEA) follows.

The Zero Reject Principle

A free, appropriate public education is guaranteed for all children ages 3-21 regardless of the severity of the individual's disability. Children under three may be provided services if state law, regulation, or judicial ruling mandate them. In Connecticut, services are currently provided to children under age 3 through Part H of IDEA.

Nondiscriminatory Assessment

A multidisciplinary team must conduct an evaluation in the child's primary language or mode of communication, using observations and non-biased, validated instruments. The child must be evaluated in all areas related to the suspected disability. The assessment should allow the child to display his or her capabilities and strengths, as well as his or her needs and difficulties.

Individualized Education Plan (IEP)

An appropriate Individualized Education Plan must be written for each child. This legal document should be developed during a team planning meeting composed of parents, a school administration representative, the child's teacher, members of the evaluation team, and others (such as a physician) invited by the parents or the school. The IEP will contain a statement of the child's current level of performance; long term goals and short term objectives; specific educational services the child will need; the date for beginning services, and the anticipated duration of the services; the extent of the child's participation in the regular or mainstream education program; and how to determine whether the goals and objectives for the child are being met.

Least Restrictive Environment (LRE)

To the maximum extent possible, schools must educate children who have disabilities with their peers who do ***not*** have disabilities. To provide the Least Restrictive Environment for children:

- Special classes, separate schooling, or otherwise removing a student with disabilities from regular education should occur only when the nature or severity of the disability is such that education in regular classes cannot be achieved satisfactorily even with the use of supplementary aids and services.
- Schools must provide a spectrum of placement options (regular classes, regular classes with minimal support, regular classes with one-to-one assistance, special education classes, etc.), and supplementary services (adaptive physical education, speech and language, etc.).
- Schools must provide education as close to the student's home as possible, and allow a student to participate in extracurricular and nonacademic activities to the extent appropriate.
- The school must work to return a child with disabilities placed outside of the regular education classroom back into the regular classroom as soon as possible.

Due Process and Parent Participation

School districts must establish and follow specific procedures in order to protect the rights of children and their families. Due process procedures must include the following components:

- Parents may examine all records pertaining to their child.
- Parents have the right to obtain an independent evaluation of their child, in addition to that provided by the school district and its staff.
- Parents must be given the opportunity to consent or object to the identification, evaluation, or placement of their child. They must be informed of the team planning conference and encouraged to participate. Meetings must be scheduled at times convenient for parents and appropriate communications must be maintained with them.
- Parents or guardians must receive written notice if a change is proposed in their child's classification, evaluation, or educational placement.
- Parents have a right to an impartial due process hearing conducted by a hearing officer, and/or mediation if they are in disagreement with the school district. Parents have the right to be represented by a lawyer, to give evidence, and to cross-examine. Hearings may be requested by the parent or by the school district.
- Surrogate parents must be appointed to provide representation and informed consent for children whose parents or guardians are not known, or who are not available.

Chronology of Laws and Key Components

1975 The Education for All Handicapped Children Act (P.L. 94-142)

Part B of The Education for All Handicapped Children Act requires: that states furnish all children with disabilities (ages 6 to 21) a free, appropriate public education in the least restrictive environment; the provision of special education and related services designed to meet the unique needs of these children; and the development of an Individualized Educational Plan for each child.

1986 Amendments to The Education for All Handicapped Children Act (P.L. 99-457)

The addition of Part H requires: the development of "a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers (birth to three years of age) with disabilities and their families"; the establishment of a State Interagency Coordinating Council; and the development of an Individualized Family Service Plan for each eligible infant or toddler and his or her family. Part B is expanded to include special education preschool services for children from ages 3 to 5.

1990 The Americans with Disabilities Act (ADA)

ADA is a wide-ranging civil rights law that prohibits discrimination against people with disabilities or physical and mental impairments that substantially limit their activities such as working, walking, talking, seeing, hearing, or caring for themselves. ADA requires that employers make reasonable accommodations for employees with disabilities and the prohibition of discrimination in commercial facilities and in any activity or service operated or funded by state or local government, including daycare centers and other programs which serve children ***without*** disabilities.

1991 Individuals with Disabilities Education Act (P.L. 101-476, IDEA)

The change from the "Education for All Handicapped Children" to the "Individuals with Disabilities Education Act" reflects shifts the terminology from "**handicaps**" to "**disabilities**", use of people first language (a person *with* a disability, a child *with* cerebral palsy), and encompasses all of the components from The Education for All Handicapped Children Act and its amendments.

1994 Families of Children with Disabilities Support Act (sec. 315 of P.L. 103-230)

Under this act all programs, projects, and activities receiving federal funds from IDEA must demonstrate the practices of family centered care. The law provides nine principles that ensure family centered and family directed programming.

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Part A-General Provisions

Special Education

Special education is defined as "specially designed instruction, delivered at no cost to the parent, to address the unique needs of the child" in accordance with an Individualized Education Plan (IEP). The child may receive this instruction in the classroom, in the home, in hospitals, and in other settings, such as community early childhood programs.

Eligible Disabilities

Under Part A, general provisions, eligible disabilities include:

- Mental retardation
- Hearing impairments
- Speech and language impairments
- Visual impairments, including blindness
- Serious emotional disturbance
- Orthopedic impairments
- Autism
- Traumatic brain injury
- Other health impairments
- Specific learning disabilities

Related Services

These include transportation and other developmental, corrective, and supportive services as required to assist a child with a disability to benefit from special education. They include:

- Speech therapy

- Audiology
- Psychological services
- Physical and occupational therapy
- Recreation, including therapeutic recreation
- Early identification and assessment of disabilities in children
- Counseling services, including rehabilitative counseling
- Medical services for diagnostic or evaluative purposes
- School health services (e.g., tube feeding, suctioning, catheterization, etc.)
- Social work services in schools
- Parent counseling and training

Transition Services

These are designed for secondary-age students. They include a coordinated set of activities that promotes movement from school to post-school living, including post-secondary education, vocational training, integrated employment, supported employment, continuing adult education, adult services, independent living, and community participation. These long term, outcome oriented activities are based on the individual student's needs, preferences, and interests and are incorporated into the student's **Individual Transition Plan** no later than his or her ***16th birthday***. A statement of interagency roles, responsibilities, and linkages must also be incorporated. The local education authority is responsible for initiating transition planning for students with disabilities with the cooperation of representatives from adult services agencies.

Part H-Early Intervention Services for Infants and Toddlers

Under Part H of IDEA, early intervention services for infants and toddlers (ages birth to three) must be provided within a statewide, comprehensive, coordinated, multidisciplinary, and interagency model of service delivery. The components of this service delivery model are described below.

Lead Agency

Each state is to designate a lead agency that will be responsible for the administration of funds under Part H. In Connecticut, the lead agency has recently shifted from the **State Department of Education** to the **Department of Mental Retardation.**

State Interagency Coordinating Council

Each state is required to establish a State Interagency Coordinating Council (ICC) whose role is to advise and assist the early intervention lead. Members of the state ICC are appointed by the Governor, in accordance with the following federal guidelines:

- At least 20% of the membership must be parents of children with disabilities, birth through age twelve.
- At least one representative from the state legislature.
- At least 20% of the membership must be providers, both public and private, of early intervention services.
- At least one person representing the training of personnel.
- At least one representative of the state governance of insurance.
- Other members representing the state agencies involved in early intervention services for infants and toddlers with

disabilities and their families (Education, Mental Retardation, Children and Families, Health and Addiction Services, Social Services, Office of Protection and Advocacy, Board of Education and Services for the Blind, and Commission on the Deaf and Hearing Impaired.).

Point of Entry

The **Comprehensive Child Find** system is established as the point of entry into the early intervention system. This system must include procedures to ensure that all eligible infants and toddlers are identified, located, and evaluated. Connecticut has a single point of entry through **INFOLINE**, a statewide service that provides referral to Birth to Three services, as well as information of other community based services for children and families.

Individualized Family Service Plan (IFSP)

Each eligible infant or toddler and his or her family shall receive a multidisciplinary assessment and, based on information from these evaluations, an Individualized Family Service Plan (IFSP) will be developed.

Service Coordination

A service coordinator is appointed and is responsible for assisting an eligible child and his or her family to receive the rights, procedural safeguards, and services that are provided under the early intervention program. Service coordinators serve as the single point of contact for the family and all service providers. Service coordination is provided at no cost to the parents.

Payment

As Part H does not come under a free, appropriate education, the lead agency will establish "policies related to how services to children eligible under this part and their families will be paid for." In addition, "the inability of the parents of an eligible child to pay for services will not result in the denial of services to the child or the child's family." (P.L. 101-476, Section 303.520). Thus, early intervention services are provided ***at no cost*** to families.

Types of Services Available under Part H

Assistive technology device: using any item, piece of equipment, or product system to increase, maintain, or improve the functional capabilities of a child with disabilities. Examples include a switch controlled toy, picture communication board, or a feeding chair.

Assistive technology services: directly assisting in the selection, acquisition, or use of an assistive technology device. Examples include fittings for a specific devise, maintenance, and ongoing training and support.

Audiology: identifying children with auditory impairments; referral for medical and other necessary services; provision of auditory training; determination of the child's need for individual amplification.

Family training, counseling, and home visits: providing services of social workers, psychologists, and other qualified personnel to assist the family of a child in understanding the special needs of the child and enhancing the child's development.

Health services: enabling a child to benefit from other early intervention services, including such services as clean intermittent catheterization; tracheostomy care; tube feeding; changing of dressings or colostomy collection bags; other health services; and consultation by physicians with other service providers concerning the special healthcare needs of children that must be addressed in the course of providing other early intervention services.

Medical services only for diagnostic or evaluative purposes: diagnosing and evaluating to determine a child's developmental status and need for early intervention services. These services must be provided by a licensed physician.

Nursing services: assessing a child's health status; providing nursing care; provision of nursing care to prevent health problems, restore or improve functioning, and promote optimal health and development; administration of medications, treatments, and regimens prescribed by a licensed physician.

Nutrition services: conducting individual assessments; developing and monitoring plans to address the nutritional needs of children; making referrals to community resources to carry out nutrition goals.

Occupational therapy: addressing the functional needs of a child related to adaptive development, adaptive behavior and play, and sensory, motor, and postural development designed to improve the child's functional ability to perform tasks in home, school, and community settings.

Physical therapy: promoting sensorimotor function through the enhancement of musculoskeletal status, neurobehavioral organization, perceptual and motor development, cardiopulmonary status, and effective environmental adaptation.

Psychological services: administering psychological and developmental tests and other assessment procedures; interpreting assessment results; obtaining, integrating, and interpreting information about the child's behavior, and the child and family conditions with regard to learning, mental health, and development; planning and managing a program of psychological services.

Service coordination: coordinating all services across agency lines; serving as the single point of contact; assisting parents in gaining access to early intervention services and other services identified in the Individualized Family

Service Plan; coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) as needed.

Social work services: evaluating the child's living conditions and patterns of parent-child interaction; preparing a social or emotional developmental assessment of the child within the family context; providing counseling to parents, other family members, and the child and parents together; identifying, mobilizing, and coordinating community resources and services to enable the child and family to receive maximum benefit from early intervention services.

Special instructional services: designing learning environments and activities that promote the child's acquisition of skills in a variety of developmental areas, including cognitive processes and social interaction; planning a curriculum that will achieve the outcomes in the child's Individualized Family Service Plan; providing families with information, skills, and support related to enhancing the skill development of their child; working directly with the child to enhance development.

Speech/language pathology: identifying children with communicative or oropharyngeal disorders, or delays in the development of communication skills; referral for medical or other professional services; provision of direct services.

Transportation and related costs: covering the cost of travel (e.g., mileage, or travel by taxi, common carrier, or other means) and other costs (e.g., tolls and parking expenses) necessary for the child and the child's family to receive early intervention services.

Vision services: evaluating and assessing visual functioning, including the diagnosis and appraisal of specific visual disorders, delays, and abilities; referral for medical or other professional services; communication skills training; orientation and mobility training in all environments; visual training; additional training necessary to activate visual motor abilities.

A Self-Check for Understanding IDEA

- ☐ Do I understand the five basic components of IDEA?
- ☐ Am I aware of the eligible disabilities and related services available to children ages 3-21 under the general provisions of IDEA?
- ☐ Do I know the Lead Agency for administration of funds for early intervention services in Connecticut?
- ☐ Have I had contact with individuals who serve on the Local Interagency Coordinating Council for the community in which I practice?
- ☐ Do I know how the Comprehensive Child Find system is set up in Connecticut, and how to contact the point of entry for early intervention services?
- ☐ Am I aware of the components of the Individualized Family Service Plan?
- ☐ Do I understand the role of the service coordinator in early intervention, and do I know who the service coordinator is for children with disabilities in my practice?
- ☐ Am I aware of the types of services available to children ages birth to three?
- ☐ How do I provide family members with information about IDEA, as well as other laws that serve children?

TIPS

Family Centered Healthcare

Family centered care is both a philosophy and a set of practices originally developed by the former Surgeon General, C. Everett Koop, M.D., Sc.D. As a philosophy it encompasses the key premises of "best practices" in healthcare and in early intervention programming. Best practice requires the provision of services that are comprehensive, collaborative, coordinated, family centered, culturally competent, and community based. In 1994, the **Families of Children with Disabilities Support Act** was passed. The language of this law is landmark in its approach to family support. While passed unfunded, the intent is to provide financial incentives to states that develop comprehensive family support systems. The law established a comprehensive, coordinated system of family support that avoids duplication of services, makes efficient use of existing resources, and prevents gaps in services to families of children with disabilities. The primary goal of Act was the establishment of a state **Family Support Council**, the composition of which is 66% parents. The Lead Agency of the Connecticut Family Support Council is the Department of Mental Retardation. The Family Support Council is charged with overseeing the implementation of state programs that:

Families are and should be the center of service delivery systems designed to meet their needs and those of their children.

- Strengthen the family and maintain family unity.
- Enable all children with disabilities the opportunity to grow up within their family.
- Enable children and families to find the support services they need to have typical lives in the community.
- Reduce the costs to families who care for children with disabilities at home.
- Provide a quality of life comparable to that of similarly situated families who do not have a child with a disability.

- Enhance the capacities of all family members.

The major premise of the family centered approach in healthcare ***and*** early intervention is that the child is a member of a family, and that family is the ***center of care*** that provides for the child's development and well-being. Family centered care supports family members in their natural care giving roles, promotes typical patterns of living, and ensures that family members have choices in the provision of services to their child. To practice in a family centered manner, it is important to build relationships based on mutual trust and respect.

Principles of Family Centered Care

The original philosophy of family centered care has been expanded to incorporate nine principles that provide guidance for developing systems of care ***and*** service delivery models for children with disabilities and special healthcare needs, while also supporting the needs of families. The nine principles include:

① ***Recognizing that the family is the constant in the child's life, while the service systems and personnel within those systems fluctuate.***

Children with disabilities and special healthcare needs move through multiple service delivery systems and are involved with many different healthcare professionals, service providers, and specialists. However, throughout the child's life family members play the central and consistent role in their child's life. Since family members are the constant, it is essential to value their judgment, observations, beliefs, and hopes.

② ***Facilitating family-professional collaboration at all levels of healthcare.***

Healthcare plans should be developed collaboratively with families, physicians, and other healthcare and service providers. The healthcare plan needs to reflect the family's strengths and be tailored to meet the family's needs as defined by the individual members. Skills for alliance building and collaboration are essential to this process.

③ ***Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.***

Each family has its own beliefs, values, strengths, and needs. To be culturally competent, it is necessary to not prejudge a family or impose one's own values or cultural expectations on the family.

④ ***Recognizing family strengths and individuality, and respecting different methods of coping.***

Each family defines itself differently and has its own strengths and sources of support, which professionals can help to identify. Families nurture and respond to children's needs differently and ***all parents*** wish to feel competent in caring for their children. There must be recognition and respect for the uniqueness and strengths of each family system and each of its members.

⑤ ***Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information.***

Parents need to have access to information about their child. This information should be shared in language that is clear and understandable, including diagnosis, prognosis, treatment options, and available resources. With complete information, parents are better able to make informed decisions about the care of their child and to participate as equal partners in providing that care.

⑥ ***Encouraging and facilitating parent-to-parent support and networking.***

Support from other families with similar experiences can be extremely valuable. Through parent-to-parent contact, family members can develop a network of resources and information, enhance their practical skills for providing care to their child, and gain emotional support from others who may truly understand.

⑦ ***Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into healthcare delivery systems.***

A comprehensive healthcare plan should incorporate the medical, developmental, and social needs of the child, and the needs of family members in caring for their child. The healthcare plan should encourage each child and family to have as normal a life as possible.

⑧ ***Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families.***

Family support protocol suggests that families have access to ***"whatever it takes"*** to enable them to maintain their integrity as a family, and their goals and visions. The family's needs may include financial support, respite, child care, service coordination, parent-to-parent support, transportation, adaptive equipment, assistive technology, housing modifications, and advocacy. Professionals can play a vital role in linking families to these resources.

⑨ ***Designing accessible healthcare systems that are flexible, culturally competent, and responsive to family identified needs.***

Inflexible or fragmented service delivery systems are often a greater source of stress for families than the daily care of their children. Healthcare and service providers need to attend to the ever-changing needs of each child and family with a flexible, accessible, and responsive system of services.

A Self-Check for Family Centered Healthcare

The Family as Constant

- ☐ How do I help family members identify their needs, concerns, and priorities?
- ☐ How can I be more consistent in seeking family members' input and observations about what works and what does not work in caring for their child?
- ☐ How can I ensure that my recommendations take into account the family's needs and concerns?

Collaboration

- ☐ In what ways can I encourage parental participation in all phases of the child's care and in the decision making process?
- ☐ How can I effectively and efficiently communicate with other healthcare professionals and service providers who provide services to this family?
- ☐ How can I become more available for consultation with other healthcare professionals and service providers?

Honoring Diversity

- ☐ How can I become more attuned to the family's cultural values and belief systems, particularly when making recommendations for treatment and intervention?

Strengths and Individuality

- ☐ What strategies can I use to help family members identify their own strengths?
- ☐ What strategies can I use to help family members identify their own sources of support, both formal and informal?
- ☐ How can I become more aware of the strengths and needs of the family as a whole, and each of its individual members?

Sharing Information

- ☐ In what ways can I become better at providing family members complete information about their child in terms of diagnosis? Prognosis? Treatment options? Available resources?
- ☐ How can I ensure that the information I present is clear and understandable? Is it presented in the family's primary language?
- ☐ How can I more fully support parents' decision making skills, and respect their decisions?

Support Networks

- ☐ In what ways can I encourage the family to seek support from other families and appropriate agencies?
- ☐ In what ways can I best provide families with information about other sources of support?

Developmental Needs

- ☐ How can I ensure that my recommendations for treatment allow parents to attend to the "typical" developmental needs of their child and to the "typical" needs of family life?

Policies and Programs

- ☐ Do I inform families of agencies, programs, and services that can assist them in dealing with all of the concerns related to the care of their child?

Healthcare

- ☐ How can I be proactive and respond in a timely manner to the changing needs of each child and family?
- ☐ How can I ensure that my services accessible and flexible to meet these changing needs?
- ☐ What more can I do to ensure that the services I provide are in keeping with the principles of Family Centered Care?

TIPS

Cultural Competence

Diversity exists in many forms: race, gender, age, language, physical characteristics, disability, sexual orientation, economic status, parent/family status, education, geographic origin, profession, life style, religion, and any other conceivable difference. Best practices in pediatric care and early intervention call for open, supportive, and responsive environments in which differences are valued and encouraged. If an open environment is to be created, everyone involved needs to be aware of his or her attitudes, beliefs, and actions and how these may impede or enhance work with those who are viewed as different.

Cultural competence requires a move from ignorance, prejudice, discrimination, and stereotyping toward an awareness and respect for diversity. A desire to expand one's knowledge of cultural differences and how these impact interactions with children, families, and colleagues is essential. Cultural competence refers to specific skills that help translate beliefs, attitudes, and orientation into actions and behaviors in daily interactions with children, families, and colleagues. It is the capacity to recognize and respond to the needs of those who are different from oneself.

> **"Every person is, in many respects, like all other people, like some other people, like no other person."**
>
> **C. Kluckhohn & H. A. Murray (1948)**

The term ***cultural*** is used to describe patterns of behavior, communication, customs, beliefs, values, and institutions of a specific racial, ethnic, religious, or social group. In actuality, cultural differences exist even between different professional groups and between the "culture of" the medical profession and the "culture of" the family. In parent-physician alliances each of member needs to understand the differences that the other brings to the task of providing care to a child with disabilities or special healthcare needs. Parents, and healthcare and service providers all bring unique beliefs, concerns, priorities, and responsibilities to the situation. These can be viewed as ***cultural differences,*** and require attention in the same manner as other more commonly thought of cultural differences. In forming equal partnerships, these differences need to be honored and respected.

Cultural competence builds upon the principles and practices of family centered care. Understanding the family within their cultural context is an essential factor in providing care to the child and ultimately to the entire family. The cultural context as defined by the family is often the primary support network for that family. The following set of principles and values will provide guidance in assuring that culturally competent healthcare is being given to all children and their families.

Respect for difference and diversity

Professionals need to increase their awareness of and respect for difference, value diversity, and view diversity as an asset to care practices. Cultural patterns determine behavior and choices that families make regarding the care of their children. Exploring and gaining knowledge of the family's culture, and its differences in beliefs, practices, interpersonal and communication styles, and life view is necessary for developing cultural competence. Individuals have their own definitions of health and family, and their thought patterns and behaviors are based on these perspectives. In understanding the cultural context and preferences of families, one can more capably support their ability to recognize problems, make choices, and take responsibility for creating solutions.

The capacity for cultural self-assessment

What professionals bring to their interactions with others is impacted by personal experiences and cultural backgrounds. Thus, an awareness of one's own cultural beliefs and behaviors and how they influence interactions with others is essential.

The dynamics of difference

There are dynamics that occur when people from different cultures interact. Professionals need to be aware of how this affects the helping process. Difference can create discomfort or conflict. There may be misunderstandings, a history of distrust, or errors in judgment and expectations between individuals from different cultural backgrounds. One needs to address these dynamics openly and with sensitivity.

Flexible service models

Services and service models need to be adapted to meet the needs of diverse populations. This flexibility needs to be incorporated into office practices and policies. Service provision needs to fit the family's cultural context, and to be truly accessible, acceptable, and available. It is important to develop help-giving practices that are culturally supportive and enriching, and that allow families to feel comfortable in medical settings.

Culturally appropriate resources

Families must be linked with natural informal support systems and helping networks within the community. Natural support systems include the extended family, the neighborhood and community, spiritual and religious groups and leaders, places of worship, schools or daycare programs, etc.

> **"The absence of cultural competence anywhere is a threat to competent services everywhere."**
>
> **T. L. Cross, et. al. (1989)**

A Self-Check for Cultural Competence

- ☐ What can I do to show respect for the individuality of each person and family with whom I work?
- ☐ How can I more effectively demonstrate a respect for diversity and an acceptance and appreciation of differences?
- ☐ How can I become more open to learning about the culture and beliefs of families, particularly related to the care of their children?
- ☐ How can I become more attentive to the "cultural differences" that exist between being a healthcare provider and being a parent?
- ☐ How can I become more aware of how my cultural background effects my perceptions, behaviors, and choices both in my life and in my work?
- ☐ How can I demonstrate that I am willing to consider differences in viewpoint?
- ☐ What strategies can I use to discuss disagreements openly with family members?
- ☐ How can I more fully support parents as they define problems and make decisions within their own cultural context?
- ☐ How can I ensure that the services provided through my practice are flexible enough to meet each family's needs?
- ☐ In what ways can I help family members find natural sources of support within the community?
- ☐ What more can I do to ensure that my office functions in a culturally competent manner?

TIPS

Care Coordination and The Medical Home

Changes in the field of providing care to children with disabilities and special healthcare needs require the incorporation of social systems and family systems perspectives in addition to clinical perspectives. Best practices in primary care show that family centered, comprehensive, coordinated, and community based services are most effective in meeting the needs of children and their families. Families need to be recognized as the primary caregivers and advocates for their children, and to be supported in these roles. An expanding set of responsibilities and skills are now required of physicians and other healthcare providers.

> **"To be fully effective, health supervision must be part of a seamless system, integrated with other health and human services such as secondary and tertiary care..., child care centers, early intervention programs, mental health centers, diagnostic and evaluation programs, schools, family support centers...."**
>
> **M. Green (1994)**

Key Aspects of the Physician's Role

Identification

Identifying disabilities, developmental delays, high risk situations, and special healthcare needs; and providing developmental evaluations, screening, surveillance, and assessment.

Referral

Referring children with delays, disabilities, or special healthcare needs to early intervention services, the special education system, and other agencies or sources of support, both medical and nonmedical.

Support

Helping family members identify their own concerns, priorities, and resources; providing regular and accessible communication to families; and connecting families with community resources and informal support systems.

Collaboration

Participating in the process of developing and implementing the Individualized Family Service Plan (IFSP) or Individual Education Plan (IEP); and providing consultation with the service coordinator or case manager and other service providers.

Coordination

Providing coordination for all the child's healthcare needs; assuring continuity of care; and communicating with other healthcare providers.

Partnering

Viewing families as partners in the care of their children and in their ability to act as advisors to the medical practice.

> **"If such medical and healthcare services truly are to prepare the child to participate optimally in the continuum of other early intervention services, an inherent component of the process must include involvement of the pediatrician and the child's medical home in the planning, implementation, and monitoring of the healthcare and medical components of the child's IFSP."**
>
> **American Academy of Pediatrics (1995)**

F. Gallagher and C. Garland (1994) outline an extensive set of competencies for physicians and healthcare providers who provide care to infants and toddlers with disabilities. These competencies reflect the practices above and include specific objectives for identifying children, assessing abilities and disabilities, developing and implementing Individual Family Service Plans, and for transitioning children from early intervention services to the public school system.

Obstacles to Referring Children for Services

Physicians and other healthcare and service providers may be reluctant to suggest that parents seek early intervention services for their child. This may avert or delay the identification or diagnosis of developmental difficulties or at risk situations for children No one wants to unnecessarily alarm parents. However, delays or reluctance on the part of the healthcare provider may increase parental anxiety and cause the child to miss essential early intervention opportunities. Obstacles to making referrals may include:

- Needing more knowledge, awareness, or experience in terms of specific delays or disabilities.
- Being concerned about the parent's emotional reactions to the "bad news" or assuming that the parents are "not ready" to hear the information.
- Not acknowledging what parents communicate in terms of their concerns, observations, and hunches.
- Wanting to use a "wait and see" approach.
- Not wanting to unnecessarily alarm the parents with a hasty or premature diagnosis.
- Not having sufficient information to make a confirmed diagnosis.
- Being concerned about the uncertainty of prognosis.
- Wanting to assume total responsibility for the child's care without collaboration with other healthcare professionals and service providers.
- Feeling uncomfortable with the fact that there may be no successful treatment or cure, or no restoration to "normal functioning".

It is important that physicians and other healthcare providers not permit these concerns to interfere with referrals to the large number of services available for children with disabilities and special healthcare needs and the families that care for them.

The Medical Home

Establishing a "medical home[1] " for children is in keeping with best practices in pediatric healthcare ***and*** early intervention. The medical home model helps physicians and other healthcare providers deliver care to children that is family centered, community based, comprehensive, and coordinated. Opportunities are enhanced for effective collaboration between physicians, other healthcare providers, and the community agencies involved in providing services to children with disabilities and special healthcare needs and their families.

> **"A medical home supports the family, recognizes the importance of continuity, and builds upon an enduring relationship that spans a childhood."**
>
> **American Academy of Pediatrics (1995)**

The American Academy of Pediatrics supports the medical home concept where comprehensive, coordinated, and family centered healthcare can be provided to all infants, children, adolescents, and young adults, particularly those with disabilities or special healthcare needs. In an addendum to the Medical Home Statement, the American Academy of Pediatrics provides a definition of Pediatric Primary Healthcare, which encompasses provision of first contact care; diagnosis and treatment of acute and chronic disorders; management of serious and life-threatening illness; and coordinated management of health problems requiring multiple professional services.

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[1] The Medical Home Program (RE9262): Ad Hoc Task Force on Definition of The Medical Home. For more information, contact Marcia Di Verde, AAP Department of Community Pediatrics, (800) 433-9016, ext. 7621.

Services within the Medical Home Program

- Provision of preventive care including, but not restricted to, immunizations, growth and development assessments, appropriate screening, healthcare supervision, anticipatory guidance, and patient and parental counseling about health and psychosocial issues (anticipatory guidance).
- Assurance of ambulatory and inpatient care for acute illnesses, twenty-four hours a day, seven days a week, during the working day, after hours, on weekends, fifty-two weeks a year.
- Provision of care over an extended period of time to enhance continuity.
- Identification of the need for subspecialty consultation and referrals, and knowing from whom and where these can be obtained; provision of medical information about the patient to the consultant; evaluation of the consultant's recommendations, implementation of recommendations that are indicated and appropriate, and interpretation of these to the family.
- Interaction with school and community agencies to be certain that the special health needs of the individual child are addressed.
- Maintenance of central record and data base containing all pertinent medical information about the child, including information about hospitalizations. This record should be accessible, while maintaining confidentiality.

The Medical Home Program for Children with Special Needs also provides support to physicians to enhance their healthcare practices for children with disabilities or special healthcare needs. This program provides information about strategies and educational materials, as well as technical assistance to physicians, for developing a medical home program within their practice.

Coordinating Services

Often there are overwhelming numbers of healthcare and service providers involved in the care of children with complex needs. Each person's role and responsibilities need to be clearly defined. Parents must be asked what their expectations are for each of the healthcare and service providers. This will reduce the confusion parents might have as to which provider to turn to when they have a specific need. Thus, their needs will be more efficiently and effectively met. In addition, there must be clearly stated guidelines among all involved in the collaborative process.

Who Collaborates

- Parents
- Other family members
- Physicians
- Other healthcare providers
- Medical specialists
- Service providers
- Service coordinators
- Case managers
- Daycare personnel
- School personnel
- Anyone else involved in a child's care

A Self-Check for Care Coordination

- ☐ How can I enhance my system for communicating with other healthcare personnel, specialists,. and other service providers (via phone, letter, or the parents)?
- ☐ Do I know who the **care coordinator** or primary contact person is for the child's medical care? Does the child have a medical home?
- ☐ Do I know who the **service coordinator** is for children enrolled in an early intervention program?
- ☐ Do I know where to find complete medical records for a child?
- ☐ How can I enhance my communication with other healthcare and service providers routinely, under special circumstances, or when there are changes in condition and treatment?
- ☐ Am I made aware of team or IFSP meetings? How can I participate in these meetings? By phone? By letter?
- ☐ How can I ensure that other service providers, early interventionists, teachers, or the school nurse have appropriate and up to date information on the child's healthcare needs?
- ☐ Do I know who is providing preventive, routine, sick and well healthcare services for each child? Who attends to the acute or specialty care needs of the child?
- ☐ Am I certain about who is implementing and monitoring the various medical interventions for children who are involved with several healthcare providers?
- ☐ Do I feel that it is appropriate to ask parents to be responsible for sharing information between healthcare providers? If not, what system do I have in place to accommodate this need?

☐ How can I ensure parents know which healthcare provider to contact for a specific need that arises?

TIPS

Communicating with Families

For families of children with disabilities or special healthcare needs the issues, tasks, and goals of caring for their child can be extremely complex and overwhelming. Effective communication processes are essential when families, physicians, and other healthcare and service providers work together, to create successful outcomes for all involved, and particularly for the child. It is not only the ***exchange*** of information that is important for communication, but the ***process*** by which information is exchanged. Listening, questioning, and responding are basic communication skills that facilitate understanding, a supportive climate, and trust between healthcare providers and families. In turn, trustworthiness reduces the risk of communicating openly and allows everyone to work towards commonly shared goals in the care of children.

Communication that Benefits Families

Family members will often communicate important information about their life style, family values, needs, feelings, strengths, and coping strategies. They will talk about people who are supportive, what they would like to do to help their child, and concerns they need to have addressed. Professionals need to attend to what family members communicate, using effective communication skills such as:

- ***Responsive Listening*:** An active task that requires intention, energy, and constant attempts to ensure understanding. Family members will feel they are understood when we use ***verbal cues*** to paraphrase, summarize, and reflect on the feelings and information that they have conveyed. Subtle ***nonverbal cues*** also help family members to feel that what they are communicating is important. Leaning forward, maintaining eye contact, nodding, taking notes, and using vocalizations are nonverbal cues that encourage communication.

- ***Empathic Listening*:** Understanding feelings that accompany the thoughts a parent is communicating. When professionals attend to the feelings of family members, understanding, support, and trust are enhanced.

- ***Interactive Questioning*:** Seeking, clarifying, and confirming information to enhance understanding. Family members benefit when questions are specific, concrete, and focused, asked one at a time, and in ways that make them easy to answer.

- ***Responding:*** Providing comments to parents that reflect impressions, feelings, and observations. Feedback is helpful to family members when it is descriptive of reactions, rather than judgmental of their behaviors. ***Open ended*** responses show understanding, acknowledgment, support, and interest. These responses lead to continued communication and enhanced trust. ***Closed ended*** or vague and ambiguous responses tend to block communication and lead family members to feel discouraged or defensive.

- ***Dialogue*:** Combines the skills of responsive and empathic listening, interactive questioning, and responding. Dialogue ensures understanding of each others' concerns and priorities. It encourages family members to develop their own thoughts, ideas, and possibilities. Effective dialogue creates a united process, and enhances the ability to be open-ended and creative in solving problems and meeting the needs of children with disabilities and special healthcare needs.

Concerns, Priorities, and Resources

The principles of family centered care recognize that the family is at the center of the child's care and is the constant in providing that care. The skills of responsive and empathic listening, interactive questioning, responding, and dialoguing are particularly relevant for working with family members to help them define their concerns, priorities, and resources for the care of their child. Early intervention philosophy suggests that physicians, healthcare providers, and service providers can be vital in helping family members identify and meet their needs and those of their child with disabilities or special healthcare needs.

Family Needs

- Economic
- Physical & Environmental
- Food & Clothing
- Medical & Dental
- Transportation & Communication
- Vocational & Employment
- Adult Education & Enrichment
- Child Education & Intervention
- Child Care
- Recreational
- Emotional
- Cultural & Social

- ***Family Concerns*:** Needs, issues, or problems that the family identifies and seeks assistance in addressing.

- ***Family Priorities*:** A family's preferences and choices for which services will be provided and how these services are implemented.

- ***Family Resources*:** The strengths and abilities of family members, as well as the formal and informal support systems that can be utilized to meet the family's stated concerns and priorities.

When helping families define their concerns, priorities, and resources, one needs to remember that ***family members*** determine which concerns, priorities, and resources are relevant to their life style, life view, and their child's development.

Carl J. Dunst and colleagues (1988) developed a taxonomy of "need categories" that can be used to help families identify their needs. They also developed The Family Needs Scale and The Family Support Scale, valuable tools for identifying a family's needs and resources or support networks. (See pages 40-41).

Conveying Difficult Information

Sharing diagnostic information with parents about their child can be difficult and complex for physicians and other healthcare providers, as well as for the parents. Having a child with disabilities or special healthcare needs can impact the family and its functioning in different ways. It is important to consider how each family can be affected in these areas:

- Family dynamics, interactional patterns, and decision making.
- Family planning and participation in the community.
- Finances and employment.
- The spousal relationship, sibling relationships, and relationships with extended family members and friends.
- Roles and responsibilities in caring for the child.

It is a family's right to have complete information about the child's illness or disability. How that information is conveyed will make a difference in how parents understand and cope with what they are told. With complete information, parents can make informed decisions about the care of their child. Additionally, the alliance with family members is strengthened, and parents can actively participate as partners in caring for their child.

The issue is not *whether* to share information, but *how* to share information

Presenting information in an organized manner, and providing family members opportunity for discussion and questions is helpful in ensuring their understanding. Following are some guidelines for conveying difficult information to families.

Family history session

The family history session is a time to explore parents' ideas about the problem, etiology of the symptoms, insights, observations, and expectations. It should be acknowledged that parents have a great deal of expertise about their child. Parents need to understand that history taking is necessary to gain a better sense of their concerns and questions, and that they are not being judged or blamed.

Presentation of findings

When presenting information about the child, a dialogue must be created among family members and team members. Rather than a one-way presentation, effective communication skills can be used to ensure that parents understand what is discussed and ask questions when clarification is needed. During the presentation of findings or information about the child, the following suggestions will help parents feel more comfortable and be more receptive:

- Strongly encourage parents to bring others who will be supportive of them.
- Review parents' observations and concerns.
- Discuss concerns for the child in clear, understandable language. Connect the parents' observations and concerns to clinical understanding. Diagnostic and clinical terminology can be presented later.
- Link observable manifestations to internal processes and provide reasons for what parents observe.

Diagnosis and clinical findings

At this point parents need to hear the diagnostic and clinical terminology, as ***not*** using it may leave them fearful and uncertain.

- Explain the terminology in understandable, clear, and concise language.
- Provide information that is specific, complete, and accurate.
- Discuss diagnosis, prognosis, treatment options, and recommendations. Parents need to feel that they have choices about the treatment for their child.
- Ask parents whether the information makes sense to them or whether they need clarification or additional explanation.
- Provide parents the opportunity to ask questions. Recognize that they may be overwhelmed at this point, and may not have questions until later. Assure them that you will be available to address their questions at a later time.
- Discuss referrals to early intervention and additional healthcare services.
- Provide information about parent support networks, organizations, and advocates. Ask if they would like another parent to contact them, as they may not reach out for support.
- Have printed resource materials about the child's diagnosis available.
- Immediately provide a written report that summarizes the discussion, the clinical findings, diagnosis, and recommendations.
- Identify and explain the levels of care the child will need and the responsibilities of all care providers.

Family Member Reactions

Each family and each individual in that family will react differently to learning that one of its members has a disability or healthcare need. A wide range of emotions and behavioral responses are possible and professionals need to find ways to be sensitive to, not critical of these responses.

It is important to let family members know that their feelings are acceptable and that they may experience many feelings at the same time. They need to know that their feelings are understandable, adaptive, and normal responses to a significant life change. Parents need support to explore their fears, worries, confusion, questions, and other emotional responses. Parents may need help to identify their needs for additional emotional support. When parents explore their feelings in a supportive environment, their ability to move toward active parenting and to make decisions about treatment is enhanced. When parents are perceived to be "non-compliant", it is the professional's responsibility to assess whether they have been helped to identify and express ***their*** needs, and whether those needs have been addressed. ***All parents*** want to feel competent. When their self-identified needs are met, they can fully participate in caring for their child.

Providing Support to Parents

- Be available and approachable.
- Assure parents that you will do whatever it takes to respect and preserve the integrity of their family life.
- Respect parents' need to have hopes, dreams, and expectations for their child.
- Acknowledge parents' competencies and ability to do what they believe is best for their child.
- Convey a belief that every child has potential and will develop.
- Support normal living patterns in the home and community with treatment that is least disruptive to the child and family.
- Offer suggestions for resources and support within the community.
- Allow yourself to say ***"I don't know, I'm not sure, I'll find out".***

Family Needs Scale [1]

Name ______________________ Date ____________________

This scale asks you to indicate if you have a need for any the of help or assistance in 41 different areas. Please circle the response that best describes how you feel about needing help in those areas.

To what extent do you feel the need for any of the following types of help or assistance:	Not Applicable	Almost Never	Seldom	Sometimes	Often	Almost Always
1. Having money to buy necessities and pay bills	NA	1	2	3	4	5
2. Budgeting money	NA	1	2	3	4	5
3. Paying for special needs of my child	NA	1	2	3	4	5
4. Saving money for the future	NA	1	2	3	4	5
5. Having clean water to drink	NA	1	2	3	4	5
6. Having food for two meals for my family	NA	1	2	3	4	5
7. Having time to cook healthy meals for my family	NA	1	2	3	4	5
8. Feeding my child	NA	1	2	3	4	5
9. Getting a place to live	NA	1	2	3	4	5
10. Having plumbing, light, heat	NA	1	2	3	4	5
11. Getting furniture, clothes, toys	NA	1	2	3	4	5
12. Completing chores, repairs, home improvements	NA	1	2	3	4	5
13. Adapting my house for my child	NA	1	2	3	4	5
14. Getting a job	NA	1	2	3	4	5
15. Having a satisfying job	NA	1	2	3	4	5
16. Planning for future job of my child	NA	1	2	3	4	5
17. Getting where I need to go	NA	1	2	3	4	5
18. Getting in touch with people I need to talk to	NA	1	2	3	4	5
19. Transporting my child	NA	1	2	3	4	5
20. Having special travel equipment for my child	NA	1	2	3	4	5
21. Finding someone to talk to about my child	NA	1	2	3	4	5
22. Having someone to talk to	NA	1	2	3	4	5
23. Having medical and dental care for my family	NA	1	2	3	4	5
24. Having time to take care of myself	NA	1	2	3	4	5
25. Having emergency health care 5		NA	1	2	3	4
26. Finding special dental and medical care for my child	NA	1	2	3	4	5
27. Planning for future health needs	NA	1	2	3	4	5
28. Managing the daily needs of my child at home	NA	1	2	3	4	5
29. Caring for my child during work hours	NA	1	2	3	4	5
30. Having emergency child care	NA	1	2	3	4	5
31. Getting respite care for my child	NA	1	2	3	4	5
32. Finding care for my child in the future	NA	1	2	3	4	5
33. Finding a school placement for my child	NA	1	2	3	4	5
34. Getting equipment or therapy for my child	NA	1	2	3	4	5
35. Having time to take my child to appointments	NA	1	2	3	4	5
36. Exploring future educational options for my child	NA	1	2	3	4	5
37. Expanding my education, skills, and interests	NA	1	2	3	4	5
38. Doing things that I enjoy	NA	1	2	3	4	5
39. Doing things with my family	NA	1	2	3	4	5
40. Participation in parent groups or clubs	NA	1	2	3	4	5
41. Traveling/vacationing with my child	NA	1	2	3	4	5

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[1] C.J. Dunst, C.M. Trivette, & A.G. Deal (1988). May be reproduced.

Family Support Scale [2]

Name ______________________ Date ____________________

Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family.

Please circle the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child(ren):	Not Available	Not at all Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents	NA	1	2	3	4	5
2. My spouse or partner's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My spouse or partner's relatives/kin	NA	1	2	3	4	5
5. Spouse or partner	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My spouse or partner's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parent groups	NA	1	2	3	4	5
12. Social groups/clubs	NA	1	2	3	4	5
13. Church members/minister	NA	1	2	3	4	5
14. My family or child's physician	NA	1	2	3	4	5
15. Early childhood intervention program	NA	1	2	3	4	5
16. School/daycare center	NA	1	2	3	4	5
17. Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
18. Professional agencies (public health, social services, mental health, etc.)	NA	1	2	3	4	5
19. ____________________	NA	1	2	3	4	5
20. ____________________	NA	1	2	3	4	5

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[2] C. J. Dunst, C. M. Trivette, and A. G. Deal (1988). May be reproduced.

A Self-Check for Enhancing Communication

- ☐ How can I better demonstrate that I listen to and value parents' viewpoints, perceptions, observations, and suggestions?
- ☐ How can I be sure that parents have time for questions?
- ☐ How can I ask hard questions in easy ways?
- ☐ When communication seems to be breaking down, what can I do to initiate remedial actions?
- ☐ How can I ensure that I speak in language and terms that parents understand?
- ☐ How can I more fully support and encourage parents' efforts to learn about their child's condition?
- ☐ What strategies can I use to improve my ability to listen without judgment?
- ☐ What strategies and activities can I use to help family members achieve what they want for their children and themselves?
- ☐ How can I more fully assist families in making informed choices?
- ☐ Do I offer recommendations as options? How can I demonstrate an acceptance of or a respect for parents decisions?
- ☐ Do I recognize that the needs and wishes of the child and family will change over time?
- ☐ How can I communicate with the child to protect and foster a positive self image? How can I encourage and support an older child in understanding the implications of diagnosis and treatment and o managing their own illness or disability?

TIPS

Collaboration and Alliance Building

Parents, physicians, and other healthcare and service providers need to work as partners to meet the needs of children with disabilities and special healthcare needs within the context of their family. Collaboration improves health outcomes for children, as well as the quality of life for the child and the family. The ability to ***mutually*** use each other's knowledge, experience, and expertise is essential for effective collaboration. Effective communication skills are the foundation of these partnerships. In addition, specific skills for collaboration and alliance building are necessary on the part of parents, physicians, and other healthcare and service providers.

> **"I work collaboratively with families not only because it's the right way to do things, but because it's the most enjoyable, energizing, and satisfying way to provide services."**
>
> **Wallace, in Bishop, Woll & Arango (1993)**

Physicians are needed as active partners in the collaborative process with parents, as are other healthcare and service providers. Parents' knowledge and intuition ***and*** the expertise of physicians and other healthcare providers become the basis on which decisions about a child's care are made. Collaboration and alliance building enhance the family members' ability to take responsibility, feel competent, and act upon their innate sense of what is best for themselves and their child. In fact, collaboration enhances the capacities of all who are involved in providing care to a child with disabilities or special healthcare needs.

New roles and expectations, as well as changes in thinking, beliefs, values, and behaviors are required as parents join physicians and other healthcare and service providers in designing, implementing, and evaluating services for the child and family. These changes may be challenging and difficult for those whose experience is based on more traditional parent-professional relationships. The principles and practices of family centered care provide a place to begin the process of building alliances. This section outlines additional skills for moving toward effective collaborations.

Elements of Collaboration

Collaboration requires mutual respect and the desire to work together to provide the best care possible for all children. In order to build mutual respect, parents, physicians, and other healthcare providers need to see each other as competent. The more competent one feels, the more "collaboratively attractive" one becomes to others. As individuals become collaboratively attractive, their expertise and knowledge are sought and valued. Differences in perspective enhance the quality of care being provided to a child with disabilities. Collaboration and alliance building require an investment in the process by parents, physicians, and other healthcare and service providers. For all involved in the collaborative process, this investment requires:

Shared Responsibility and Ownership

A commitment to the collaborative process is needed, first by finding time and creating energy for all that is required. Collaboration does not occur without thoughtful planning. To take mutual ownership of the process with families, one needs to be willing to change old ways of doing things and old beliefs. This means taking risks, releasing control, and changing how professionals view and interact with family members.

Shared Expectations and Goals

Receptivity and open communication are essential to the collaborative process. When expectations and goals are clearly expressed, work is aimed in a mutually agreed upon direction. This requires that all be flexible, negotiate, and compromise.

Shared Information, Knowledge, and Skills

Trust and respect needs to be developed and nurtured by all members of the collaborative process. Honesty, integrity, and the acknowledgment of each person's strengths and capabilities are necessary when information and expertise are shared. With this, all can participate in creative problem solving and decision making.

Shared Fears and Frustration

As part of the collaborative process, difficulties, conflicts, and disappointments require discussion. All participants need to show an ability to tolerate differences and disagreements. The collaborative process is impeded when differences and frustrations are avoided. When they are openly shared, goals and solutions are created.

Shared Hopes

Everyone needs to find ways to nurture and sustain the investment, and not allow energy to fade. When each person continually shares their hopes and changing expectations, the process remains alive.

Shared Successes

The family, the child, and the healthcare providers, can share in the success and outcomes of the collaborative process. This builds momentum for the process to continue with the next set of hopes, goals, and expectations.

Creating Partnerships

All of the ***shared elements*** discussed above lead to successful outcomes and also become the benefits of the collaborative process for each of the members involved. Certain values, knowledge, and skills are needed to create partnerships and alliances with families and other healthcare and service providers. One's ability to embody these values and skills will be reflected in each interaction with families about the care of their children. C. J. Dunst, et. al. (1988) describe several help-giving practices that support alliances with families. Opportunities should be created for family members to experience competence and self-efficacy, and to acquire self-sustaining adaptive behaviors. Family members can be helped to build upon their strengths by allowing them to share the responsibility for identifying problems and concerns, creating solutions, and making the necessary changes to address their needs. Help-giving that does not promote these capabilities in parents may foster dependency and passivity, diminish self esteem, and undermine family competence and control. Partnerships are most effective when everyone ***values*** and ***practices*** positive help-giving and family centered care, and when all recognize that supporting the family creates positive outcomes for the child.

> **"Partnerships are valued over paternalistic approaches because the former implies and conveys the belief that partners are capable individuals who become more capable by sharing knowledge, skills, and resources in a manner that leaves all participants better off after entering into the cooperative arrangement."**
>
> **C. J. Dunst, et. al. (1988)**

Partnership-Building Skills

- Knowledge of the philosophies and best practices that drive early intervention and special education systems.
- Understanding of what roles and responsibilities the physician and other healthcare providers are expected to assume within the early intervention and special education systems.
- The ability to help parents identify their concerns, priorities, and resources related to their child's care and family functioning.
- The ability to help families match their needs with available resources.
- The ability to provide full, unbiased, and realistic information without extinguishing parents' hopes and dreams for their child.
- The ability to encourage the family's role in decision-making and to create opportunities for parents feel competent in caring for their child.

- The ability to listen to, empathize with, and validate parents' feelings and to recognize parents' needs to also talk with other parents for support, expertise, and resources.
- A desire to communicate with and gather information from other healthcare providers and professionals.
- A desire to advocate for families and to help families advocate for themselves.
- A desire to be accessible, available, flexible, and reliable.

Meetings with Parents

- Provide similar chairs so that all participants have equal levels of eye contact.
- Encourage family members to take notes or tape record the meeting.
- Provide facial tissues.
- Establish uninterrupted time and privacy.
- Encourage the involvement of ***all*** family members and make various time slots available.
- Ensure that key members of the multidisciplinary team are present, understanding that for some families large numbers may be overwhelming and the delivery of information may seem fragmented.
- Share the agenda with parents prior to the meeting and invite their input to the agenda.
- Provide opportunity for discussion and to meet again if needed.
- Include the child once he or she has reached an appropriate age.

Provide an opportunity for the child to speak confidentially with the doctor, when appropriate.

Resolving Conflict

Disagreements, disappointments, and conflicts will occur. Often conflicts arise because of differing goals and values, misunderstandings, or a lack of information. During conflict and times of stress it is particularly important to sustain the respect and support that has become the basis of the alliance. To do this, efforts must be made to separate the person from the problem; strive for mutual understanding, if not agreement; and be open to negotiation and compromise. Additionally, everyone needs to agree that each member has a right to own ***and*** express his or her own opinions. To resolve conflicts and reach shared decisions, each member is responsible to:

① Maintain focus on the family's concerns and priorities.

② Identify and share their understanding of the disagreement and define the problem from their viewpoint.

③ Listen to the ideas and feelings of others and use effective communication skills.

④ Generate options for solutions that can be win/win/win for the child, family, and physician or healthcare provider.

⑤ Select the best solutions for the child and family.

⑥ Reestablish our goals, action plans, roles, and responsibilities.

⑦ Monitor the action plan as it is implemented.

By successfully managing conflicts and disagreements, professionals can develop more open and trusting relationships with families. Additionally, each person is more likely to have a sense of mutual ownership for decisions and their implementation.

A Self-Check for Collaboration and Alliance Building

- ☐ What more can I do to work ***with*** family members for the well-being of their child?
- ☐ What can I do to ensure that my roles and responsibilities are clear, as well as those of family members and other healthcare providers?
- ☐ Do I truly believe parents are equal partners and have valuable expertise regarding their child?
- ☐ How can I demonstrate that I value parents' comments and insights and make use of their knowledge about their child's total needs?
- ☐ How can I encourage family members to be active participants in the decision making process?
- ☐ Do I recognize that what I perceive as a lack of cooperation or "noncompliant" behavior may mean that a parent's concerns, priorities, and needs are not being addressed? What can I do to address this?
- ☐ Do I measure outcomes in terms of progress and competencies for the child and the family? If not, how can I move toward this practice?
- ☐ In what ways can I enhance my skills for listening responsively, questioning interactively, and responding appropriately to family members?
- ☐ How can I make every effort to work with family members toward solutions and expanding resources?
- ☐ How can I strive to gain mutual understanding with family members so that we can take action as a team and alleviate any problems that arise?
- ☐ Do I continually review, evaluate, and revise action plans with parents?

- ☐ In what ways can I more effectively share with family members the responsibility for planning and implementing care for their child?
- ☐ In what ways can I encourage parents to communicate with other parents?
- ☐ How can I effectively communicate with other healthcare and service providers so that all are as informed as possible?
- ☐ How can I ensure that I am honest about the child's ability and skill levels?
- ☐ Am I effortful in sharing information that will help determine the services and treatments the child and family needs?
- ☐ How can I enable parents to contribute equally to the healthcare plan?
- ☐ How can I communicate openly with parents about disagreements or disappointments?
- ☐ How can I provide clarification, additional information, or help to parents when they are confronted with difficult decisions?
- ☐ How can I help myself to remain focused on the family's priorities and values?
- ☐ What skills can I use to negotiate fairly, without defensiveness and judgment?
- ☐ How can I demonstrate respect for the knowledge, skill, and expertise of all team members?
- ☐ What can I do to ensure that the activities, strategies, services, and treatment plans reflect shared decisions that are based on the family's chosen outcomes and values?

TIPS

Procedures for Early Intervention Referrals

Part H of the IDEA legislation mandates a Comprehensive Child Find System be established. The child find system is designed to ensure that all infants and toddlers who may be eligible for services under Part H are *identified, located, and evaluated*. These efforts are coordinated between the lead agency (in Connecticut, the State Department of Mental Retardation) and all other state agencies responsible for administering education, health, and social service programs such as Maternal and Child Health, Early Periodic Screening, Diagnosis, and Treatment (EPSDT), Head Start, etc.

Identification

Referrals to early intervention services can be made by parents, or, with the family's knowledge and consent, by anyone who has concerns about a child's development, including physicians, other healthcare providers, daycare providers, and other family members.

Procedures exist for use by primary referral sources such as hospitals, prenatal and postnatal care facilities, physicians, parents, daycare providers, public health facilities, and other healthcare providers and social service agencies.

For children ages 3-21

Referrals for evaluation and special education services are typically made to the Director of Special Education or Pupil Personnel Services at the local Board of Education.

In Connecticut referrals are made by calling:

Birth to Three INFOLINE

1-800-505-7000

BEST COPY AVAILABLE

An early intervention specialist at INFOLINE asks for basic information including the family's name, address, and telephone number, and the reason for referral. The INFOLINE person then contacts the **Regional Family Service Coordination Center** (RFSCC), which provides services for the town in which the family resides. Once the call from INFOLINE has been received at the Regional Family Service Coordination Center, a **service coordinator** is assigned.

Role of the Physician in Identification

- Recognizing factors that place a child at risk for developmental delays.
- Identifying children who have disabilities, developmental delays, or who may be at risk for delay.
- Administering and interpreting developmental screening instruments with all infants.
- Understanding the procedures for referring infants and toddlers to the early intervention system.
- Knowing what community resources are available for infants and toddlers who may or may not be eligible.
- Enhancing alliances and care coordination among secondary and tertiary care settings, risk registries, and other care providers.
- Increasing family awareness of developmental milestones, resources for assessment, the importance of early identification, and the impact of early intervention services.

Service Coordinator

Once the service coordinator is assigned, he or she contacts the child's parents, provides an overview of the early intervention system, and schedules an initial meeting with the family to begin the evaluation and assessment process. The service coordinator is responsible for coordinating all aspects of the early intervention program including: arranging the evaluation and assessment; facilitating the Individual Family Service Plan process; monitoring the delivery of all services across agency lines; coordinating with medical and healthcare providers; and serving as the **single point of contact** in helping parents to obtain the services and assistance they need for their child and the family. Parents have the right to take on the role of service coordinator themselves, if they choose to do so.

Role of the Physician with the Service Coordinator

- Establishing procedures for communication with the service coordinator and other service providers.
- Maintaining ongoing communication with the service coordinator directly and/or through the parents.

Eligibility Criteria

Any child from birth to thirty-six months of age is eligible for early intervention services under Part H if ***either*** of the following conditions are met:

① The child is diagnosed as having an **established condition**. Children with established conditions are automatically eligible for services, although they may not exhibit significant delays at the time of diagnosis. **Established conditions** include but are not limited to:

- Genetic disorders
- Chromosomal syndromes
- Sensory impairments
- Neurological syndromes and conditions
- Conditions related to significant fetal exposure to toxins
- Other physical/medical conditions, atypical developmental patterns, and psychosocial conditions known to result in significant developmental delays

② The child is identified by a multidisciplinary team as exhibiting a **significant developmental delay** in one or more of the following areas:

- Cognitive development
- Physical development, including vision, hearing, motor, and health needs

- Communication, including receptive and/or expressive language development
- Social or emotional development
- Adaptive skills

A significant developmental delay is determined by a score of two standard deviations below the mean in one area of development **or** one and one-half standard deviations below the mean in two areas of development. A child can be referred to the early intervention system **without** a formal diagnosis.

Evaluation and Assessment

The service coordinator works with the family and other service providers to select individuals who will complete a multidisciplinary assessment of the child to determine the nature and extent of his or her needs for services.

The assessment should occur, as much as possible, within the child's natural environments and include input from family members. It should be completed in the child's primary language, using non-biased assessment tools. The evaluation team documents the child's needs in each of the developmental areas including cognitive development, physical development, communication, social or emotional development, and adaptive skills. The child's strengths and competencies should also be noted. In keeping with the practices of family centered care, a **Family Needs Assessment** is also completed, with parent permission. The focus of the family needs assessment is to:

- Elicit parents' concerns and priorities related to their child's development.
- Elicit the desired outcomes or goals for the child's development from the parents and a statement of changes parents would like to see for their child and themselves.
- Identify the family's resources, strengths, and stress levels.

- Identify the parents' needs for support including services for the child, as well as support for themselves, which may include needs such as employment, financial assistance, and other community resources.

If a child is **not eligible** for early intervention programming, the healthcare provider should refer the family to other resources and services within the community. The child's development needs to be monitored in an ongoing manner. Birth to Three INFOLINE offers families the **Ages and Stages (ASQ) Child Monitoring Program**. For children who were referred to early intervention and are not eligible for services, Birth to Three INFOLINE will periodically send parents a questionnaire, which asks them to answer questions about their child's development. Questionnaires are designed to assess the child's development for every four month period up to the age of 48 months. After Birth to Three INFOLINE receives the completed questionnaire, the parents are contacted by phone or mail. Information is provided about whether their child's development is within normal limits, or whether there are concerns warranting another referral to or re-evaluation by the early intervention system.

Role of the Physician in Evaluation and Assessment

- Interpreting diagnostic information and sharing it with the family.
- Obtaining information from other early intervention service providers.
- Presenting information related to the child's medical or healthcare needs to the family and other team members.
- Providing a written medical summary or profile of the child's needs which can be used by parents and service providers.

The Individual Family Service Plan

The **Individual Family Service Plan (IFSP)** is a continuous process, as well as a document representing the child's and family's involvement in the early intervention system. The process involves a team meeting with family members, the service coordinator, the physician, other healthcare providers, the evaluators, and service providers. The IFSP process involves the following steps:

① Review results of the child's evaluations and the family needs assessment

② Develop statements of desired outcomes and priorities for early intervention services, medical or health services, and the family's needs for enhancing the child's development

③ Select specific services to meet desired outcomes and include types of services, providers, duration, frequencies, intensities, methods, locations, and payment responsibilities. Please refer Laws that Serve Children with Disabilities, pages 8-11 for a list of available types of services.

④ Prepare the IFSP document which must include:

- The present level of the child's development in six areas: medical/health, cognitive, communication, gross and fine motor, social or emotional, and adaptive skills.
- A statement of the family's concerns, priorities, and resources.
- A statement of expected major outcomes in the six areas listed in (a) above, including criteria, procedures, and timelines to determine progress and whether modifications or revisions are needed.
- A statement of early intervention services necessary to achieve the identified outcomes, including frequency, intensity, location, method of delivery, and payment responsibility.
- Other needed health, social, and economic services (that are not required by early intervention services) and the steps necessary to assist the family in obtaining these services.
- Projected dates for initiation and anticipated duration of services.

- Steps for supporting the child's transition from the early intervention program to the mandated special education program within the local school district at age three.
- The name of the service coordinator.

Best practices indicate that the child's primary physician should be an active part of the IFSP process. Communication may occur in person at the IFSP meeting, by phone, or by mail. Physicians may be asked to sign the IFSP document to show their agreement with the services that are to be provided and for insurance or Medicaid reimbursement purposes.

Role of the Physician in the IFSP Process

- Discussing with families the value of the IFSP process and early intervention services.
- Assisting families in identifying who they wish to be involved in the IFSP process and in contacting those individuals.
- Assisting the family in their preparation for the IFSP process and providing support throughout the process.
- Participating in the development of the IFSP, as a member of the team.
- Communicating about the child's medical and healthcare needs either directly or through the parents to other team members.
- Helping the IFSP team understand the impact of the child's medical needs on his or her overall development and the implications for program planning and service provision.
- For each healthcare need, documenting healthcare practices and expected outcomes for both home and daycare or school settings.
- Reviewing health related services to ensure they are appropriate and comprehensive.

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Provide and Coordinate Services

Best practices in early intervention indicate that services are most effective when they are provided in natural or integrated settings such as the child's home or daycare program. The service coordinator is responsible for scheduling and monitoring the services, as well as maintaining contact with parents, service providers, and the healthcare providers on a regular basis.

IFSP Reviews and Revisions

The IFSP is reviewed at least every six months with regard to the child's development, progress, and outcomes; status of the family's concerns, priorities, and resources; continued eligibility status; and services being provided. Parents, and other team members, with parental permission, can request an IFSP review at any time. A new IFSP is developed annually.

Role of the Physician for Providing and Coordinating Services

- Serving as the care coordinator or liaison regarding the child's healthcare needs, communicating with other healthcare providers, the service coordinator, and other early intervention service providers.
- Monitoring changes in the child's developmental status and medical or healthcare needs and communicating these changes to the family and the service coordinator.
- Reassessing the family members' needs for support and referring them to other community resources.
- Understanding the criteria which might lead to the termination of early intervention services and, if this occurs, supporting family members by referring them to other community resources.
- Providing updated information about the child's healthcare or medical needs, particularly for IFSP reviews.

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Transition to the Local Education Authority (LEA)

When a child reaches three years of age, if eligibility requirements continue to be met, services will be provided under Part B of the Individuals with Disabilities Education Act. Part B services pick up where Birth to Three services leave off. This includes preschool through high school special education and other related services for children ages three to 21. Part B services are provided by the Local Education Authority (i.e., the local or regional public school system). The transition from the early intervention system to the special education system needs to be carefully planned.

In the Birth to Three system, transition planning begins **90 days before** a child is to enter the local or regional public school system. Transition planning involves the family, members of the IFSP team, the service coordinator, and representatives from the LEA or school system. The transition process requires a review of the child's present levels of development, progress made during the early intervention program, and eligibility for preschool special education services. In addition, the transition plan includes steps for preparing the child and the family for the change in service provision systems, development of the initial **Individual Education Plan** to begin at age three, and the transfer of all records to the LEA with parental consent.

Role of the Physician for Transition Planning

- Understanding the eligibility criteria and procedures for making referrals to the local or regional public school system for preschool special education services.
- Understanding best practices and the advantages of integrated placements for children with disabilities.
- Participating in the development of the transition plan.
- Providing continued support to the family and resources for ongoing service coordination within the community.
- Working with the LEA to incorporate the child's medical and healthcare needs into the Individual Education Plan.

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A Self-Check for Referral Procedures

☐ Do I understand the Comprehensive Child Find System in Connecticut?

☐ Do I know how to make a referral to the Birth to Three system?

☐ How can I become more active in identifying children who are at risk or who have disabilities? What developmental screening procedures do I use in my practice?

☐ How can I maintain updated knowledge of the community resources available to infants and toddlers who have disabilities or special healthcare needs?

☐ How can I help family members to increase their awareness of developmental milestones and the importance of early identification and early intervention?

☐ What procedure can I create for communicating with the early intervention service coordinator?

☐ Do I understand the eligibility criteria for children from birth to three years of age to receive early intervention services?

☐ How can I more effectively participate in the evaluation and assessment phase of referral? In what ways can I provide information about the child's healthcare needs and help parents to identify their concerns, priorities, and resources?

☐ How can I participate in the IFSP process? By communicating with IFSP team members or attending IFSP meetings? How can I ensure that the child's healthcare needs are identified within the IFSP document?

☐ How can I ensure that regular updates about the child's healthcare needs are provided to parents and service providers?

☐ How can I keep informed about the early intervention services the child is receiving?

☐ Am I aware of the transition procedures and eligibility criteria for children who are about to receive services through their Local Education Authority or public school system?

☐ Am I aware of best practices in early intervention, and in preschool and special education?

☐ How can I ensure that the child's healthcare needs are addressed in the IEP?

TIPS

Community Involvement

Physicians and healthcare providers are essential members of the larger community. Beyond providing healthcare services, communities and families need physicians and other healthcare and service providers to assume broader roles. At community, state, and national levels, involvement in caring for and supporting children with disabilities and special healthcare needs and their families is essential. Professionals are responsible for creating and supporting community based services that enhance the daily lives of and families. Action must be taken to ensure that ***all*** children and families are included or integrated into the community in meaningful and enriching ways.

When designing and implementing community based systems of care, it is necessary to ensure that they are systematically developed, linked, and coordinated. To be certain that these systems of care address the needs of children and families in comprehensive, family centered, and culturally competent ways, professionals and families need to work cooperatively and collaboratively with other service providers and families in the community.

> **At this time, we will celebrate the new born children in our community. As a community, we recognize that these beautiful children are the seeds of our heritage, fruits of our labor, and the future of our people. We must protect them, we must educate them, and we must love them. As a community, we must share these responsibilities.**
>
> **Ghanian Ceremony**

Community Based Efforts

Healthcare, education, mental health, and social service organizations need to work toward decreasing duplication of efforts, as well as gaps in available resources. This can be accomplished when programs are coordinated, integrated, and collaborative. On the community level this means:

- Clearly identifying services available under each agency or organization.

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- Creating information exchange systems across organizations.
- Including service providers and families on planning and policy boards for community organizations.
- Ensuring continuity of care by planning for transitions in services.
- Providing support to personnel in social and educational organizations to acquire skills necessary for integrating children with special healthcare needs or disabilities.
- Building public awareness.
- Creating family support systems.

Public Awareness

To support and integrate children with disabilities and their families in the community, there must be an increase in public awareness about the developmental needs of children, and the specific needs of children with disabilities and their families Community members can be helped to appreciate the mutual rewards of integrating every child and family into community life. Public awareness activities may include:

- Creating outreach efforts to identify children in need of services and to inform community members about the needs of children with disabilities and special healthcare needs.
- Using local employers, businesses, and civic organizations as leaders in increasing public awareness and in recognizing and meeting the needs of children and their families.
- Asking parents to educate the community and service providers about the strengths and needs of their children.

Resource-Based Practices

Carl J. Dunst and his colleagues have developed strategies for identifying and mobilizing community based resources and experiences that can help meet the needs of children with disabilities and their families. A community may be a geographic neighborhood, or a "location" where social, emotional, spiritual, educational, recreational, vocational, or other needs are met. Thus, there are multiple sources of community support that can be accessed to meet the needs of children and families. Community resources may involve specific services, as well as assistance, information, experiences, and any other opportunities that promote the development of children and the well-being of families. Resource-based supports are:

- Community centered, rather than professionally centered.
- Informal ***and*** formal.
- Built around enhancing the strengths and capacities of children and families.
- Broadly available to all members of the community.

The family needs taxonomy discussed on pages 35-36 can be used to help families identify their needs and concerns. The following steps can be used to identify community based resources and sources of to address the needs that families have expressed. This list is adapted from the work of Carol M. Trivette and her colleagues.[2]

① Identify all resources within the community and indicate the actual locations of these resources on a map (community resource mapping).

② Identify the needs and concerns, as well as the strengths of children, individuals, families, and the community as a whole.

---

[2] Trivette, C. M., Dunst, C. J., & Deal, A. G. (Draft). Resource-Based Early Intervention Practices. Chapter prepared for a forthcoming book by S. K. Thurman, F. R. Cornwell, & S. R. Gottwald (Eds.), The contexts of early intervention: Systems and settings. Baltimore: Brookes Publishing Co.

③ Identify the experiences children and families need to gain competence.

④ Identify any concerns or barriers to meeting the needs of children and families.

⑤ Match the identified needs with the resources on the map.

⑥ Find additional resources on the map that can help to eliminate the barriers.

Community Based Supports

Families can be helped to identify the supports that are already in place, and those that are still needed. Often parents are unaware of support systems that exist. Suggestions should be based on the parents' identified needs, priorities, and concerns. Following is a comprehensive list of services that can be made available in any community to support children with disabilities and special healthcare needs and their families.

- ***The Family:*** immediate and extended; spouse or partner; parents; grandparents; in-laws; brothers and sisters; aunts and uncles.
- ***Informal Networks:*** friends; neighbors; parent-to parent networks; parent support groups; co-workers; baby sitters; car pool partners; sibling support groups.
- ***Social Organizations and Associations:*** church or synagogue members; religious or spiritual groups or leaders; artistic organizations; business organizations; charitable groups and drives; civic events; child and family advocacy groups; elderly groups; ethnic associations; fitness groups and sports leagues; special interest clubs; men's and women's groups; self-help groups; outdoor clubs; community service clubs; social cause groups; veteran groups; youth groups; local museums, science centers, and zoos.
- ***Community Programs:*** community colleges; institutions of higher education; social, leisure, and recreational programs; camps; libraries; community

healthcare centers and clinics; police and fire departments; employment agencies and vocational support services; legal assistance agencies; housing assistance; in-home healthcare services; childcare or daycare centers, baby sitter services, and play groups; adult continuing education; volunteer services; respite care; parenting classes; homemaker services; food and nutrition referral resources; the YMCA or YWCA.

- ***Professionals:*** physicians and other healthcare providers; hospital personnel; daycare, school, and early intervention personnel; agency personnel; service providers; service coordinators and case managers; counselors, social workers, and therapists.
- ***Financial:*** healthcare and financial planning programs, insurance reimbursements, entitlement programs (Medicaid, Children with Special Health Care Needs, Social Security Income).
- ***Policy Makers:*** agency directors, school boards, city council, legislators at community, state, and national levels; political organizations.
- ***Other:*** information and referral services (INFOLINE); adaptive equipment loan and exchange programs; interpreting services; transportation assistance; barrier-free community facilities.

Advocacy

Professionals, family members, and other citizens need to closely evaluate public policy and community resources that relate to children with disabilities and special healthcare needs and their families. Advocating for these members of the community involves:

- Accessing funds through grants, private foundations, corporations, public resources.
- Accessing data regarding the utilization of resources.
- Identifying opportunities for providing or receiving training in advocacy skills.

- Communicating with public agencies and legislative bodies.
- Testifying at public hearings.
- Lobbying for policy changes.

Families as Advisors

Community based systems of care and support services are enriched when families provide input. The values, opinions, and perspectives of families that have children with disabilities or special healthcare needs should be major ingredients for shaping policy and program design, and for implementing practices at organizational and community levels. As advisors, family members can directly influence policies, programs, and practices that impact the care and services children and families receive. In this role, family members gain valuable skills, competencies, and confidence. Organizations and services in the community can benefit greatly when family members share their unique perspectives, observations, insights, ideas, and experiences. Parents can help to identify problems, and can be resourceful in creating solutions, even when faced with limited supports and resources.

Family members should be recruited and provided with leadership training so that they gain an understanding of the skills and expectations that go along with their new role. Family members can be involved in an advisory role formally or informally, in an ongoing manner or for a one-time focus group activity. When an organization involves family members in advisory roles, it is beneficial to include those who are new to the early intervention system, as well as those who are currently receiving services, and veterans. Representation should reflect the community in terms of racial, ethnic, socioeconomic, and cultural backgrounds. Finally, more than one family should be invited to participate.

Parents and other family members can serve as advisors in various ways. Some of these advisory roles include:

- Members of task forces, boards of trustees, and advisory boards.
- Program consultants and evaluators.

- Participants in needs assessment processes, quality improvement initiatives, and consumer satisfaction surveys.
- Co-trainers for preservice and inservice sessions, participants and presenters at conferences, and group facilitators.
- Witnesses at hearings.
- Advocates for themselves, and other children and families.
- Members of committees hiring new staff.
- Advisors to medical practices, the educational system, and social service agencies.

Involvement in the community enhances the quality of services and the quality of life for children with disabilities and special healthcare needs and their families. Professionals benefit from the opportunity to learn more about family strengths, resources, and individuality outside of the clinical setting. Community involvement ensures that programs and services truly met the ***self-identified*** needs of families with children who have disabilities and special healthcare needs.

> **"...families are visionaries. Their dreams are not tied to bureaucratic limitations. Their ideas and hopes for their children, their families, and their communities provide challenge, inspiration, and guidance."**
>
> **E. Jeppson & J. Thomas (1994)**

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A Self Check for Community Involvement*

☐ How can I demonstrate the belief that parents have unique perspectives and experiences that can enrich our relationship and the care I provide to children?

☐ How can I ensure that family members participate in decision making at program and policy levels for my medical practice, community organizations, and agencies?

☐ How can I demonstrate the belief that family members bring a critical element to the healthcare team that no one else can provide?

☐ In what ways can I invite parents to provide input, feedback, and suggestions about office practices, as well as the care of their child?

☐ How can I be more respectful in considering seriously the opinions of family members?

☐ How can I encourage family members to look at the bigger picture, beyond their own specific needs?

☐ How can I encourage parents to take on advisory roles either in my office practice, or in organizations and agencies within the community?

☐ Do I support parents in taking on these advisory roles by providing clear expectations, leadership training, and by delegating responsibilities to them?

☐ How can I work with other organizations, agencies, and local businesses to ensure public awareness activities and family support services are available within the community?

☐ Hew can I be a better advocate for children and families?

* Adapted from **Essential Allies: Families as Advisors.**

TIPS

Tools for Enhancing Care

To enhance the care provided to children with chronic medical conditions within the primary care setting, W. Carl Cooley, MD has developed suggested guidelines and "office tools" for medical offices. These materials are also useful for providing care to children with disabilities. Dr. Cooley has generously permitted us to share his ideas and materials for this booklet. These materials are provided by the New Hampshire Partners in Health Project, at the Hood Center for Family Support of the Dartmouth Hitchcock Medical Center, Dartmouth, New Hampshire. The New Hampshire Partners in Health Project is funded by The Robert Wood Johnson Foundation and by project #MCJ-337062 from the Maternal and Child Health Program (Title V, Social Security Act).

In keeping with best practices in primary care ***and*** early intervention, these suggestions for enhancing services to children with disabilities and special healthcare needs and their families embrace the philosophies of family centered, community based, coordinated care. Dr. Cooley's model, referred to as **Chronic Condition Management** (CCM), is described as "a specific primary care practice which acknowledges that children with chronic conditions and their families may require more than the usual well child preventive care and acute illness interventions." (Cooley, in press). In the Chronic Condition Management model the child's special healthcare needs are addressed in conjunction with his or her primary pediatric care needs, such as well child care and acute condition care. This model is also extremely useful with children who have disabilities.

When children have complex medical needs, confusion about the roles and responsibilities of the various healthcare providers and other service providers may exist for the providers, as well as the family. Explicit discussions need to take place to address:

- Who will provide which set of healthcare services to the child?
- When is the primary care physician contacted rather than one of the child's specialists?
- How will communication occur between physicians? Between the physician and the school nurse? Between the physician and other service providers?

- Who will coordinate the child's care and treatment plan?

A set of materials and office tools has been developed to enhance services within the primary care setting, collaboration with early intervention service providers and school personnel, and the overall coordination of care. Again, Dr. Cooley has permitted us to share these materials as part of the TIPS booklet. They can be used as examples for creating office tools within any medical practice. **Please do not copy these materials.**

Office Tools

The office tool materials are designed to be color coded and/or have a clearly identifiable design. These include:

- ***External Chart Identifiers:*** Color coded stickers that alert staff that this child is a patient with special healthcare needs (Page 84).
- ***Alert List:*** A list of all patients with special healthcare needs to alert office staff that considerations for specialty scheduling (convenient times, longer appointments) should be given to the family (Page 85).
- ***Coded Phone Message:*** A color coded phone message for use when a parents call about their child (Page 86).
- ***Templates:*** Page forms for referral or progress notes to specialists, informational letters to school nurses, the School/Primary Care Communication Note, and referral to financial support programs (Pages 87-89).
- ***Resource Information:*** A notebook with information about community and regional resources for families including social service agencies, financial support programs, local parent support groups, etc.

Care Coordination Tools

These care coordination tools are designed to guide the family and the healthcare provider through an office visit so that all of the concerns, priorities, and needs for resources related to the child's care are addressed.

- ***Agenda - Primary Care Office Visit:*** An attachment to the chart to remind the healthcare provider(s) to ask family members about their needs for: information about their child's care; printed educational materials; additional supports and resources; or communication with other healthcare or service providers (Page 90).
- ***List of Healthcare and Other Service Providers:*** A single page sheet in the file that serves as a reference to all other services and providers involved in the child's care and supporting the family (Page 91).
- ***Care Planning Sheets:*** The first page provides space to indicate family concerns, healthcare provider's concerns, medical updates, information about other supports in the child's and family's life, and financial needs. The next two pages provide space for indicating tasks that need to be accomplished, who is responsible for following through with the tasks, and additional care notes (Pages 92-93).
- ***Critical Aspects of Care Guide:*** Single page "Healthwatch" guidelines for the care of various chronic conditions (Page 94).

Child Care Tools - A Parent's Notebook

This notebook is given to parents of children with disabilities and special healthcare needs to enhance their participation in the management of their child's care. It is designed to help parents organize their contacts with various healthcare providers and other service providers and to record concerns, questions, and changes needed in their child's care. The contents of the parent's notebook include:

- ***Care Providers:*** Phone numbers and addresses of the primary care physician, other healthcare providers and specialists, and other service providers.
- ***Medical Care Details:*** Information about medication and dosage, tests completed and results, family and child medical history, immunization records, and medical appointment notes.
- ***Personal Notes:*** Suggested questions that parents may ask about services for their child, scheduling considerations, illnesses, general check ups, medication, tests, referrals to specialists, surgery and hospitalization, and the child's questions and concerns.
- ***Care Needs:*** Emergency plans, emergency contacts and phone numbers, baby sitter's guide, information for caregivers, daily routines, and special instructions.
- ***School Issues:*** Suggestions for contacting school personnel, preparing for meetings, discussing the child's needs, developing an action plan, communicating about the child's special healthcare needs and the impact in school, physical education activity guide, forms for communication between school personnel and the physician, permission to disseminate medication at school and to administer specialized healthcare procedures, and documentation of training for staff on specific healthcare procedures.
- ***Information and Resources:*** A list of organizations, contact persons, services they provide, and other information related to the needs of the child and the family.
- ***Business:*** Information about health insurance, Medicaid, and other entitlement programs.

Dr. Cooley suggests that the Chronic Condition Management model be used if a child's disability or healthcare needs significantly impact daily living, family life, school performance, or the child's development. This model of primary care may also be helpful when a child requires ongoing specialty care, the involvement of multiple service providers and agencies, or during crises or times of significant family stress related to the child's healthcare status.

Once the decision is made to use this care model with a child and his or her family, it should be implemented in an organized manner. The model needs to be discussed with the parents (and the child, if appropriate). Specifically, parents and physicians need to clarify expectations, roles, and responsibilities. Parents should be given the name of a primary contact person within the office. The child's chart should be set up and marked with the chart identifiers described above. Dr. Cooley outlines suggestions for periodic visits at the primary care level to monitor children with special healthcare needs. During these monitoring visits the following should be addressed:

- Identify the parents' current concerns.
- Identify the healthcare provider's current concerns.
- Assess changes since the previous visit.
- Assess the current health status of the child.
- Review outcomes of any specialty contacts or visits.
- Review the impact of special healthcare needs on the child's life, and school performance, family life, emotional coping, financial resources.
- Determine if parents need additional educational materials, resources, referrals.
- Determine the need for further consultation with specialists, other service providers, or school personnel.
- Review and revise care priorities and action plans.

A Self-Check for Enhancing Care

- ☐ What system can my office develop for identifying the charts of children with special healthcare needs?
- ☐ How can I ensure that office staff are aware of the families who may need special scheduling considerations?
- ☐ What can my office do to develop standard formats for consultations or communications with other healthcare providers, daycare or school personnel, and other service providers?
- ☐ How can my office maintain lists of various resources for information and community support available to parents?
- ☐ How can I keep track of others who are involved in a child's care? Is a list of all other healthcare and service providers attached to the child's chart?
- ☐ What format can I develop for recording parent concerns, as well as my concerns for the child's care and for planning how those concerns will be addressed?
- ☐ How can my practice help family members organize the often overwhelming amount of information they need to have about their child?
- ☐ What other things can be done in my office to enhance the care provided to children with disabilities and special healthcare needs?

The following section is a set of sample materials from Dr. W. Carl Cooley and the New Hampshire Partners in Health Project, which is funded by The Robert Wood Johnson Foundation and by project #MCJ-337062 from the Maternal and Child Health Program (Title V, Social Security Act). These samples are provided as suggestions that can be used to develop office procedures for enhancing the care provided to children with disabilities and special healthcare needs and their families. **Please do not duplicate these materials.**

External Chart Identifiers
(Color Coded)

Chronic Condition Management
In the Primary Care Setting

New Hampshire Partners In Health
Office Partners Project

CHRONIC CONDITION MANAGEMENT IN PRIMARY CARE

Notes/Contact:

____

____

____

NH Partners In Health Office Partners Project

CHRONIC CONDITION MANAGEMENT in PRIMARY CARE

FAMILIES FOLLOWED (ALERT LIST)

1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

NH Partners In Health
Office Partners Project

Coded Phone Message

PHONE MESSAGE

FOR ____________________ **DATE** _________ **TIME** _________

FROM ____________________ **RE:** ________________________

PHONE #: ________________ **BEST TIME:** __________________

MESSAGE: ____

____

____

CHRONIC CONDITION MANAGEMENT in PRIMARY CARE
NEW HAMPSHIRE PARTNERS IN HEALTH OFFICE PARTNERS PROJECT

Referral for Specialty Consultation

Child's Name
Date: **Specialist referred to:**

Clinical Problem:

Specific Questions I need answered:

Parent/Child Concerns:

Ongoing Care desired:

__ Consultation without ongoing subspecialty care
__ Phone discussion about specific shared roles in disease management
__ Chronic condition management locally between subspecialty visits
__ Subspecialty management of all aspects of the chronic condition with acute and primary care locally.

Easiest time to contact me:

I would appreciate receiving a recent update or review article on:

Doctor's name: ________________________
Clinic title: ________________________
Street address: ________________________
Town, state, zip code: ________________________
Telephone number: ________________________

Enclosed:
__ office/hospital progress notes
__ lab results
__ X-rays (__ family will hand carry)

NH Partners in Health
Office Partners Project

Communication with School or Daycare Program

To: ______________________________ Date: __________

Child's Name: ____________________

Date of Birth: ____________________

The child named above is a patient of mine whose parent(s) have asked me to notify school personnel that he/she has a chronic medical condition which may at times affect attendance, performance, or health at school. Though specialists may be involved in the management of this condition, I would like to be your primary resource regarding the health or medical management of this student. Please feel free to contact ____________ at my office with any questions regarding this child's needs at school.

Chronic medical condition(s) affecting this child:

____

____

Current medications and my orders if administration at school is needed:

____

____

____

Restrictions, suggestions, or special instructions:

____

____

____

If you need further information about this child's chronic medical condition to assist with meeting his/her educational needs please let me know. His/her parent(s) or legal guardians have given consent by their signature below for you to contact me regarding school-related issues and to inform me if his health is seriously impacting on school attendance or performance.

Sincerely,

I hereby consent to communication and exchange of information regarding my child _________________________ between _________________________ and my child's school principal, school nurse, or classroom teacher(s) at ____________________ school regarding health issues that may impact on his/her performance at school.

_________________________ __________________

parent's or guardian's signature date

NH Partners in Health Office Partners Project

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SCHOOL/PRIMARY CARE COMMUNICATION
(Postcard Format)

TO ______________________________

FROM ____________________________ PHONE _______

I am the primary care doctor/school nurse for _____________

Office/School ________________________________

I have a question/concern/about _____________________

____

____

Please call me as soon as you can @ ( ) _________ or ( ) _________

Best Time ______________________________________

Other ____

New Hampshire Partners in Health Office Partners Project

Please respond, fold & return!

____

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____

AGENDA: Primary Care Office Visit

Name ______________________ **Date** ________________

Any questions about the following?

- ☐ Medication/Treatments
- ☐ School Needs
- ☐ Med Education-Child/Family
- ☐ Financial
- ☐ Family Support
- ☐ Specialty Care
- ☐ Home Health/Community Services
- ☐ Other ____________________

FAMILY ISSUES AND CONCERNS THIS VISIT:

____

____

____

PRACTICE ISSUES AND CONCERNS THIS VISIT:

____

____

____

Chief Complaint:

Type Visit:

Care Coordination:

New Hampshire Partners in Health Office Partners Project

List of Healthcare and Other Service Providers

Child's Name: ____________________ **DOB:** ________________

Dx: ______________________

Health Care:	Name/Location	Phone #	Fax #	Referral Date
Specialists:				
Special clinics: (coordinators)				
Other:				

School Services:	Name/Location	Phone #	Fax #	Effective Dates
Early intervention:				
School attending:				
School principal(s):				
Classroom teacher(s):				
School nurse(s):				
Spec. ed. coordinator:				
Other personnel:				

Community services:	Name/Location	Phone #	Fax #
Family support coordinator:			
Visiting nurse:			
Mental health provider:			
HMO/Insurance contact:			
DCYF case worker:			
Other service providers:			
Informal supports: (minister, friend, etc.)			

New Hampshire Partners in Health Office Partners Project

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Chronic Condition Management in Primary Care
Care Planning

Parent's Names ______________________ / ______________________

Child's Name ______________________ Diagnosis(s) ______________

Phones (H) __________ / __________ (W) __________ / __________

Best Time/Place To Call ______________ FAX # if available ________

CCM Monitoring: Questioning & Interventions in the following areas:

Date: / / /

Family's #1 Issue				
Health Provider's #1 Issue				
Chronic Condition Update (meds, acute episodes, etc.)				
Child's Life/ Recent Accomplishments:				
Family Life				
Comm/Family Support Issues				
Financial Issues (insurance, SSI, etc.)				
School Needs				
Specialist Contacts				
Patient Education/ Self Care				
Other				

PARENT NOTEBOOK GIVEN (DATE) __________ OFFICE CONTACT PERSON ______________

New Hampshire Partners in Health Office Partners Project

Chronic Condition Management in Primary Care
Next Steps Needed

Child's Name ____________________ Phone Number ____________________

Diagnosis(s) ____

Date	Task	Who	Notes	Date Done

Next appointment needed:

Next CCM monitoring visit:

Review Date / / / / / /

New Hampshire Partners in Health Office Partners Project

FIGURE 2 Healthwatch for the Person with Down Syndrome Adapted with permission from Crocker and Rubin (1989)

CONCERN	CLINICAL EXPRESSION	WHEN SEEN	PREVALENCE	MANAGEMENT
congenital heart disease	complete AV canal septal defects mitral prolapse	newborn or first six weeks; later for mitral prolapse	40-50%;	Pediatric cardiology consultation; echocardiogram; surgery; dental prophylaxis
hypotonia	reduced muscle tone; increased range of joint movement; motor function problems	throughout life; tends to improve with age	100%	guidance by physical therapy early intervention program
delayed growth	usually near or below third percentile of general population for height	throughout life	100%	nutritional support; DS growth charts check heart/thyroid; ? growth hormone in future
developmental delays	some global delay, degree varies; specific processing problems; specific language delay	first year; monitor throughout life	100%	early intervention individual educational plan language intervention
hearing problems	middle ear problems (fluid and infections) sensorineural hearing loss	screen in first six months; recheck annually	50-70%	audiology, tympanometry ENT consultation myringotomy tubes if needed
vision problems	refractive errors strabismus cataracts	eye exam in 1st month; then annually	50% 35% 15%	pediatric opthalmologic consultation and appropriate treatment
cervical spine problems	atlanto-axial instability skeletal anomalies may cause spinal cord injury	initial x-ray screen at 3 years old	15%	orthopedic; neurology; neuro-surgery; avoid high risk activity; surgery if spinal cord compression
thyroid disease	hypothyroidism (rarely hyper-)	some congenital; check annually	15%	endocrinology consultation; replacement therapy
overweight	excessive weight gain	late preschool; adolescence/adult life	common	life style changes around food/exercise; check thyroid function; ? depression
seizure disorder	generalized or myoclonic; hypsarrhythmia	any time	5-10%	neurology consultation, EEG, medication
emotional problems	behavioral changes; depression	adolescence; young adult	common	inclusive education; counseling; support during transition from school to work

variable occurrence of: gastrointestinal anomalies; Hirschsprungs; leukemia; alopecia areata; diabetes; sleep apnea; hip dysplasia

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Other Products

The following products have been developed as part of the Physicians Training Project and may be obtained by contacting the Division of Child and Family Studies as indicated on the inside cover of this booklet.

Early Intervention and Special Education in Connecticut - The Physician's Role A set of nine training manuals designed to be used with medical students and pediatric or family practice residents. Each manual contains objectives, background information, a family study, discussion questions and answers, and a case resolve. The nine manuals cover the areas of Family Centered Care, Education Law, Research Efficacy, Role of Other Disciplines, Curriculum Development, Natural Instructional Environments, Service Coordination, Team Process, and Collaborative Consultation.

A Physician's Reference - Services for Children with Disabilities and Their Families A booklet of fact sheets describing programs and agencies in Connecticut that provide a variety of services and supports to children with disabilities and their families. Each description includes general information about the program, who is eligible, what services are provided, and whom to contact for further information or to make referrals.

A Family's Reference - Services for Children with Disabilities and Their Families A booklet of fact sheets describing programs and agencies in Connecticut that provide a variety of services and supports to children with disabilities and their families. Each description includes general information about the program, who is eligible, what services are provided, and whom to contact for further information or to make referrals.

Working Effectively with Families and Their Children with Disabilities A curriculum guide designed to enhance the clinical rotation experience of pediatric residents who are working with children with disabilities and special healthcare needs. This curriculum incorporates a protocol for a home visit and a day care or school visit, as well as self-study manuals on Family Centered Care, Education Law, and Team Process.

Notes